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DOCTOR OF PHILOSOPHY

Understanding risk perceptions and responses of the public, healthcare professionals and the media the case of *Clostridium difficile*

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Understanding risk perceptions and
responses of the public, healthcare
professionals and the media: the case
of *Clostridium difficile*

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“You have your way, I have my way. As for the right way, the correct way, and the only way, it does not exist”

Friedrich Nietzsche

“If you have lived with the fear of failure all your life, you tend to erect a window of risk aversion. In every opportunity, you first see the risks, the downsides, the possibility of failure. Someone else may look at the same image through the window of optimism and see a huge, overpowering silver lining.”

Prakah Iyer

“Most people do not listen with the intent to understand; they listen with the intent to reply”

Stephen R Covey

To Chris, Alana and Jack in thanks for the faith they had in me to
do this and for all the support and encouragement they gave me
while doing it

A Brief Summary

How risk is understood, made sense of, and responded to, by different public and professional groups is poorly understood and open to debate. To some degree, this is dependent upon the theoretical perspective from which risk perceptions are studied. While current theory is useful in providing broad insight into risk perceptions and responses to risk, a more comprehensive situated understanding is needed in relation to specific health-related risks.

Healthcare associated infections are a global threat to public health and a major cause of morbidity and mortality. *Clostridium difficile* (*C.difficile*) in particular, is one of the most common healthcare associated infections, causing significant harm, widespread public concern and considerable media interest.

The purpose of this study was to explore risk perceptions and responses of the public and healthcare professionals within the context of *C.difficile*, and to examine the role of the media in health-risk reporting as such reporting is an important backdrop to public and professional understanding and knowledge.

The study employed a media coverage analysis of a major *C.difficile* outbreak, used eight public focus groups (a total of 39 participants) and seven healthcare professional focus groups (a total 29 participants), and employed ten semi-structured interviews with media professionals.

The analysis demonstrated how *C.difficile* was constructed and communicated to the public and confirmed that media accounts were frequently used by the public and healthcare professionals to make sense of infection risk. What emerged from the focus groups was a conceptual framework that provides a generic account of the way in which people construct and communicate risk. This was then fleshed out in the detailed context of *C.difficile*. In seeking further exploration of the production of health-related risk in the media, the

media professionals provided accounts of their role, and the strategies adopted when representing health-related risks. Overall, the study found a range of factors that influence how people perceive and respond to risks, which have significant implications for future risk management and communication within the context of *C.difficile* and also for wider health-related risks.

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Publications from this study

BURNETT, E., et al., 2014. Constructing identities in the media: newspaper coverage analysis of a major UK *Clostridium difficile* outbreak. Journal of Advanced Nursing, 70(7), pp. 1542-1552.

BURNETT, E., et al., 2013. Understanding factors that impact on health care professionals' risk perceptions and responses toward *Clostridium difficile* and meticillin-resistant *Staphylococcus aureus*: A structured literature review. American Journal of Infection Control, 41(5) pp. 394-400.

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Conference Presentations

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Abstract

My original contribution to knowledge is the emergence of an inductively derived conceptual framework that provides a generic account of the way in which people construct and communicate risk. Within this framework, a detailed contextual understanding of how this was applied to *C.difficile* is developed. Furthermore, in seeking to place responses to health risks in the wider social, cultural and political context, moving beyond a standard critique of media output, an understanding of both how and why the media report health-related risks helped identify ways in which the media can influence how people can construct and communicate about risks.

The incidence and severity of *C.difficile* infection is increasing and it is one of the most common healthcare associated infections, posing a global threat to public health. With the occurrence of major outbreaks within the UK and elsewhere, fear, confusion and unsafe infection prevention and control practices continue to exist among the public and healthcare professionals. Consequently, *C.difficile* is of particular interest to the media, being the focus of much media reporting.

How the public perceive and respond to a health-related risk is shaped by a range of socially and contextually structured evaluations and interpretations, based on a range of factors such as availability heuristics, direct and indirect experiences and social influences, particularly those emanating from the media. Expert risk perceptions and responses on the other hand, are

sometimes supposed to be more veridical than those of the public because they are based on calculations of scientific probabilities. Risk perceptions and responses however are context dependent and therefore to be understood, need to be considered within the context that they are perceived and experienced. There is currently little risk perception empirical research to draw upon within the context of *C.difficile*.

The aim of this study was to explore risk perceptions and responses of the public and healthcare professionals within the context of *C.difficile* and to examine the role of the media in health-related risk reporting. This qualitative study adopted three approaches to data collection: a media coverage analysis of a major *C.difficile* outbreak, focus groups with the public and healthcare professionals in two geographical areas (an outbreak versus a non-outbreak area), and in-depth, semi-structured interviews with media professionals.

The media coverage analysis found that the media portrayed key individuals involved in the outbreak as victims, villains and heroes. These 'characters' evolved as the outbreak progressed and new information became available. Such representations were frequently used as a backdrop for the public and healthcare professionals in order to support or refute their perceptions about *C.difficile*.

For the public and healthcare professionals, the consequence of *C.difficile* and why it occurred was much more salient than estimations of the probability or

likelihood of it occurring. Conceptual factors that were found to be important in influencing perceptions included: feelings of vulnerability; attribution of responsibility; judgements about competence; and evaluations of risk communicators.

Media professionals were seen as important risk communicators in the focus groups, however they saw themselves as predominantly story tellers and entertainers, rather than 'educators'. They also believed themselves to be advocates for the public whereby they uncover information that officialdom would seek to keep hidden.

What emerged from this study was a coherent, structured and generic account of how various stakeholders construct and communicate about risk. Within this conceptual structuring, a detailed contextual understanding of how this was applied by the public and healthcare professionals around *C.difficile* was gained. Findings indicate that uncertainty, fear and confusion about *C.difficile* exist that appear to be influenced by a range of contextual factors such as indirect and direct experiences, social interaction and the media. If risk management and communication strategies are to influence the desired and effective responses towards *C.difficile* and wider health-related risks, those responsible for managing and communicating risk must consider already established risk perceptions in addition to the factors that have influenced such risk perceptions.

Chapter One: Introduction

Setting the scene

This study explores public and healthcare professionals' (HCPs) risk perceptions and responses towards factors they associate with *C.difficile*. Additionally, it also examines the role of the media in health-related risk reporting. The initial idea for this study stemmed from reflecting upon my clinical experience as an infection prevention and control specialist practitioner, spanning more than 12 years in acute and primary care settings. As I was often called upon to speak to patients and their families following the acquisition of a healthcare associated infection, I frequently witnessed the immediate distress that this caused. As a result, I spent a considerable amount of that time talking to them, telling them what I thought they needed to know. Similarly, I also spoke to the clinical staff, again telling them what I thought they needed to know in order to 'manage the infection' and prevent further spread. I was therefore satisfied that I had 'educated and informed'.

However, it was not until I embarked on my first qualitative research study following a move from clinical practice to academia that I began to realise the true extent of how limited our understanding of people's perceptions around healthcare associated infections were. For that study, I interviewed previous hospital in-patients who had been discharged home after having acquired a *Staphylococcus aureus* blood-stream infection whilst in an acute hospital (Burnett et al. 2010). Despite my years of clinical practice, listening to the

enormity of how this experience had affected them and their families was upsetting and at times quite uncomfortable to hear.

That study forced me to think about how diverse people's views, opinions, beliefs and feelings were in relation to healthcare associated infections, in that what was perceived to be important for one person was not always the same for another. Yet, when providing information to patients, relatives and also clinical staff as an infection prevention and control practitioner, I took little cognisance of this variation. As a result, I realised that the information I provided often did not take account of this. It therefore struck me that how could I have addressed what was important to each person I 'educated and informed' if I did not have an understanding of their views, opinions and beliefs?

Not long after that study, another major *C.difficile* outbreak occurred in Scotland which resulted in a number of serious illnesses and deaths. Not surprisingly, this attracted huge media interest, which generated an array of media coverage around accusations of poor patient care and negligence. Such media coverage, as with coverage of previous *C.difficile* outbreaks, was heavily criticised by healthcare professionals for inaccurate reporting, scaremongering and creating public panic.

Through reading the public inquiry report that followed the outbreak, it was apparent that there were significant inconsistencies and inaccuracies around

information provision, communication and the management of *C.difficile*. Yet similar inconsistencies and inaccuracies had been reported in previous outbreak inquiries. The combination of the findings from my previous research study and patterns of inconsistencies emerging from *C.difficile* outbreaks formed the basis of my interest in exploring this further. After deciding to explore risk perceptions and responses of the public and HCPs around *C.difficile*, given the significant involvement of the media in risk communication during these outbreaks, it was evident to me that the media should also be included in this study.

Clostridium difficile

C.difficile is an anaerobic, spore-forming, gram-positive bacterium, which produces powerful toxins causing diarrhoea, inflammation and injury to the lining of the gut (Kenneley 2014). The term *C.difficile* infection (CDI) covers a broad spectrum of disease ranging from mild diarrhoea to pseudomembranous colitis (PMC) and toxic megacolon (Stanley et al. 2013). Severe cases are often fatal. Frequent and inappropriate antibiotic usage is one of the main causes of CDI in addition to person to person spread through direct contact and the environment (Donskey 2013). Recurrent CDIs are common and treatment failure rates using antimicrobial therapy are high (Rohlke and Stollman 2012, Agito et al. 2013).

Over the last few decades *C.difficile* has evolved to being the most common healthcare associated infection in acute and community settings and a major cause of morbidity and mortality among hospitalised patients (Health Protection Scotland 2009, Lyras et al. 2009, Dubberke et al. 2014). Although *C. difficile* was first described in the 1930s, it was not identified as the cause of diarrhoea and colitis following antibiotic therapy until the late 1970s (Department of Health 2007). As a result, mandatory reporting of all cases has been in place in the United Kingdom since January 2004 (Department of Health 2008). There have been a number of major, highly publicised *C.difficile* outbreaks within the UK over the past decade, such as Stoke Mandeville hospital (Healthcare Commission 2006), Maidstone and Tunbridge Wells hospitals (Healthcare Commission 2007), Vale of Leven hospital (The Scottish Government Health Department 2008) and Ninewells hospital (NHS Tayside 2010). Not surprisingly, *C.difficile* is therefore a major patient and public concern and attracts widespread media interest (Prieto and Clark 2005, Collins et al. 2009).

As incidences are currently increasing and outbreaks have continued to occur, the epidemiology of *C.difficile* has seen dramatic changes by the emergence and epidemic spread of certain strains and increasing antimicrobial resistance (Freeman et al. 2010, Rasko 2013). Thus, *C.difficile* continues to evoke significant challenges in relation to prevention, control, treatment and management (Cookson 2007, Gerding et al. 2008, Cohen et al. 2010, Walters and Zuckerbraun 2014).

While concerted efforts have been made in relation to the development and implementation of policies and guidance about *C.difficile*, fear, confusion, misunderstanding and poor practice among the public, patients and healthcare professionals is documented (Prieto and Clark 2005, Vaughan et al. 2006, Collins et al. 2009, Tsagkaraki et al. 2009, Aroori et al. 2009, Guillemin et al. 2014). Yet despite this evidence, little is known about how and why individuals perceive what they do in relation to *C.difficile* and how they subsequently respond. According to the wider risk perception literature, understanding why and how individuals make sense of and respond (both physically and emotionally) to health-related risks is crucial in successfully addressing confusion, fear, misunderstanding and inappropriate behaviour (Mak and Lai 2012, Shiloh et al. 2013).

Risk

The term 'risk' originated in the mid-17th century from the French word *risqué*, meaning 'danger' (Oxford English Dictionary 2012). According to Jacobs (2000), it originally related to the probability or mathematical likelihood of an event occurring, combined with the magnitude of the losses or gains that would likely result. However, others argue that risk is not a definitive entity because people do not merely respond to the physical impact of measureable and quantifiable risks (Burns and Slovic 2012, Waters et al. 2013). Rather, others emphasise the need for a focus to be placed on the significance of psychological, social and cultural contexts associated with a risk (Sjöberg

2000, Taylor-Gooby 2008, Chan et al. 2014). To conceptualise this, Slovic and Weber (2002, p.4) assert:

"It does not exist "out there," independent of our minds and cultures, waiting to be measured. Instead, risk is seen as a concept that human beings have invented to help them understand and cope with the dangers and uncertainties of life. Although these dangers are real, there is no such thing as "real risk" or "objective risk."

Others support this view by arguing that while risk is recognised by threats and dangers it closely relates to uncertainty in terms of situations with unknown outcomes (Sjöberg et al. 2004, Brewer et al. 2007). What is also important however, is that while risk involves exposure to potential consequences, in order for individuals to respond, they need to be concerned about them (Williamson and Weyman 2005). In other words, how people think about a risk depends on how much the potential consequences matter and how they value the outcomes at stake (Eiser 2004, Pidgeon and Fischhoff 2011).

An evaluation or judgement about a risk varies from person to person because it is learned by socially and contextually structured conceptions and evaluations in terms of what it looks like and what it should or should not be (Hampel 2006, Zinn 2008). For example, some people may care about specific threats to human life, whereas others may have more concern about the economy or the environment, thus different risk estimates, assessments

and evaluations are applied. Van Nuffelen (2004) locate this by pointing out that individuals are never separated from their social and cultural background and as a result, a single, uncontested, universal or true perception of any risk does not exist. Rather it is the social, cultural and contextual biases that condition them. It is for these reasons in order to manage and communicate risks, an understanding of how and why people perceive and respond to risks within specific contexts is crucial (Smith et al. 2002b, Setbon and Raude 2010, Seale et al. 2010).

Risk perception

Risk perceptions arise from uncertainty and are based on a person's subjective evaluations and judgements about risks and risk related choices (Williamson and Weyman 2005). However, in order for people to form an evaluation or judgement about a risk and respond to it physically and/or emotionally, they need to, at the very least, possess some knowledge or understanding about it (Meiser et al. 2001). This understanding is created by a diverse range of experiences and information. Risk perceptions are therefore mental constructs that are formed as a result of a complex process of collecting, selecting and interpreting signals about uncertain events, situation or activities (Hampel 2006).

According to Wachinger et al. (2013), through this process, risks are internalised by social and contextual learning which is constantly reinforced,

modified, amplified or attenuated through ongoing and continual risk communication processes. It is for this reason that people often make judgements and evaluations about risks and make behaviour decisions which may not align with objective scientific evidence (Heo et al. 2013). For example, research demonstrates that immunisation is one of the most effective ways of controlling illness from influenza (Jefferson et al. 2005). Yet, despite the availability of a safe and effective H1N1 vaccine, a key predictor of poor uptake is found to be the result of evolving subjective perceptions of the risks of the vaccine. In other words, people do not accept the H1N1 vaccine despite knowing the risks of illness without it, but owing to misplaced doubts about its safety (Gidengil et al. 2012). Decisions not to accept the vaccine are therefore based on subjective evaluations of risks which are clearly inconsistent to objective scientific evidence. In order to address such misperceptions and encourage behaviour change, it is therefore crucial that we understand why and how people perceive the risks and consequences of their actions (Rubin 2009).

This evidence therefore shows that risk perceptions are extremely complex as they do not stand apart from the wider constructions of everyday life and meaning (Irwin 2001). As a result, when individuals have a lack of technical or scientific understanding or knowledge about a risk, they will use a variety of evidence and their wider contextual knowledge and understanding, in order to make sense of that risk and respond to it (Horlick-Jones and Prades 2009, Wallquist et al. 2010). Horlick-Jones et al. (2007) refers to this process as a

form of 'bricolage', whereby people draw upon 'whatever is at hand' to capture the essence of their knowledge and understanding. In doing so an emerging understanding occurs. This involves the use of heuristics (Pachur et al. 2012), direct experience (Knuth et al. 2014), indirect experience (Martin et al. 2009), emotion (Sjöberg 2007), familiarity (Schmidt 2004) and controllability (Nordgren et al. 2007). Others also suggest a sense of place may be of significance (Evans Cameron 2008), although this seems to be explored to a much lesser extent in the literature.

Owing to these influences, Weinstein (2003) asserts that individuals often associate a specific risk with apparent unrelated risks, issues or situations. However, he argues that these should never simply be dismissed as incorrect or irrational. Rather, they need to be recognised as a solid part of an individual's judgement or evaluation of a risk and are important in influencing the way in which individuals respond to a risk. Weinstein (2003) further points out that risks are rarely accountable in practice to a single rationality and that different risks are often pulled together using different rationalities for making particular decisions.

Within the risk perception literature, ongoing tension and debate is apparent between public and expert risk perceptions (Hansen et al. 2003, Jensen et al. 2005, Casiday 2007). Public risk perceptions are believed to be subjective, broad and complex, involving fundamental knowledge deficits. Additionally, they are believed to be driven by emotion so they are often viewed as irrational

(Krewski et al. 2012). Common assertions of expert risk perceptions on the other hand, are reported to relate to objective, technical or statistical risk estimates and are therefore perceived as rational (Sjöberg 2002b). Consequently, risk management and communication strategies are believed to be developed with the aim of aligning seemingly irrational public perceptions of risk with the more rational ones held by experts (Frewer 2004). However, Renn (2004, p.410) argues that *“any attempt to combat political paralysis by rejecting risk perception as irrational and relying solely on expert assessment would be misguided”*. Rather, Renn (2004) asserts that risk management and communication should be guided by neither purely science-based nor subjective-based assessment, but by mutual enhancement between the two.

Risk and the media

With over ten million newspapers sold daily in the UK, they are woven into the fabric of everyday life and remain one of the biggest sources of news for the public (Wilson et al. 2008). According to the World Health Organisation (2002), the media have two major functions: first, to interpret scientific information and government policies for the public and second, to reflect the concerns of the general public to a wider national audience. It is therefore not surprising that the media can have a significant role in shaping risk perceptions, influencing policymakers and guiding the direction of scientific research (Williamson and Weyman 2005, Campo et al. 2009, Kitzinger 2009).

Over recent years, the media and in particular, newspapers, have developed an increasing fascination for *C.difficile* and healthcare associated infections in general, particularly around outbreak situations (Washer and Joffe 2006, Washer et al. 2008, Duerden 2008, Boyce et al. 2009). The dominant tendency of media representation however, in such a context is often perceived to carry alarmist and dramatic stories, frequently using emotive personal testimonies from ‘victims’ in order to apportion responsibility onto someone or something (Chan et al. 2010). As a result journalists are often blamed for inaccurate or biased reporting, committing sins of omission and sensationalism (Moynihan et al. 2000, Moynihan 2003). A possible explanation for this, according to Eldridge (1999) is that, because health risks are recognised by threats and dangers, when something goes wrong we are often confronted with human or technological failure. As a result, responses to a health-related risk, either emotionally or physically, are often shaped through people seeking to attribute causes or impute motives. For this reason, Smith (2005, p.1471) locates the media within a “*tangled web of communication and debate*” between sources and the public.

However, despite inferences made in the literature about the negative impact of the media with regards to risk perceptions towards healthcare associated infections (Hamour et al. 2003, McLaughlin et al. 2008, Collins et al. 2009, Moore et al. 2010), there is little empirical evidence to substantiate them. Accordingly, Philo (2007) argues that given the complexity of the role of the media in health-related risk reporting, if researchers wish to fully understand

this, they need to explore media representation, audience reception and media production. Only then can researchers seek to challenge stereotyping and misrepresentation and engage in more informed debates about the accuracy, quality and impact of media products (Kitzinger 1999a, Philo 1999, Stamm et al. 2003, Kitzinger 2009, Wardle and Boyce 2009).

Summary

The purpose of this study is to explore risk perceptions and responses of the public and healthcare professionals in the context of *C.difficile* and to examine the role of the media. In doing so, it aims to enhance understanding of how and why individuals and groups of individuals evaluate and judge risks factors that they associate with *C.difficile* and how this impacts on how they respond. By examining the role of the media within this context, the study aims to understand how and why the media represents and produces health-related stories so that health risk management and communication can be improved. To address the research aims the following research questions were asked:

1. How was information about *Clostridium difficile* and associated individuals framed in the newspapers during an outbreak?
2. How and why do the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?

3. Are there similarities and/or differences in the way the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?
4. What factors influence the way in which health-related risks are produced in newspapers?

A more detailed discussion of risk perceptions in the broader context and also specific to *C.difficile* and healthcare associated infection is provided in the following chapter. Additionally a closer examination of health-related risk reporting in the media and how this may impact on risk perceptions and responses is presented.

Chapter Two: Reviewing the risk perception literature

Introduction

The notion of risk perceptions and how people respond or react to risk has been a topic of interest for many researchers over recent years. Sociological, anthropological and psychological literature has contributed significantly to gaining an understanding of how risk is constructed, perceived and responded to by the public and experts from a broad perspective. However, considerably less is known about risk perceptions and responses related to healthcare, particularly around the context of *C.difficile* and healthcare associated infections in general. Context is, as asserted by Burgess (2006), intrinsic to risk in that a hazard cannot be considered a risk outside of a particular human context. In other words, risk perception depends on the context in which a risk is experienced or understood (Hampel 2006), therefore risk perceptions need to be explored within specific contexts in order to be fully understood.

The aim of this literature review therefore is to draw upon the broad evidence to gain an understanding of what factors are important in shaping risk perceptions and responses and to explore the differences between the public and experts. Additionally, this review aims to examine the literature specifically related to *C.difficile* and other healthcare associated infections and identify important gaps that require to be addressed.

This chapter is divided into five parts:

Part one critically examines three predominant theoretical frameworks used for studying risk perceptions and responses and identifies its strengths in helping to understand some important aspects of risk perceptions and responses to risk. Limitations of these approaches will also be discussed.

Part two is a scoping review of the wider risk perception literature. A scoping literature review was considered the most appropriate type of review to conduct owing to the need to identify and explore the size and scope of available risk perception literature which allowed a broad map of existing evidence to be gained (Kwak et al. 2014, Hurlock-Chorostecki et al. 2014). This then enabled the accumulation of as much risk perception-related evidence as possible to help generate a more in-depth understanding of specific issues. Additionally, this helped identify research gaps and needs from what was known about risk perception and *C.difficile* (Arksey and O'Malley 2005, Armstrong et al. 2011, Valaitis et al. 2012). The scoping literature review was guided by a broad question.

Part three consists of two structured literature reviews of risk perceptions and responses in the context of *C.difficile* and other healthcare associated infections, first from public and patients perspectives and second from healthcare professionals' perspectives. Structured reviews allow for a more focused exploration of empirical research about a specific phenomenon

compared with aiming to gain a broad understanding of a wider topic using a scoping review (Themessl-Huber et al. 2009). Having established a broad understanding of the risk perception research and recognising that how people perceive and respond to risk are context specific, a more focused literature review about risk perceptions and *C.difficile* was required. However, similar to the strategy adopted by others (Morris et al. 2012), owing to the limited empirical research specific to *C.difficile*, a structured literature review was undertaken rather than a systematic review as the search strategy was extended to also include other healthcare associated infections. Extending this search enabled a greater discussion of the literature which was of similar nature to *C.difficile*, while still allowing for gaps in current research to be identified. The structured reviews were guided by more specific questions (compared to the scoping reviews) and to ensure transparency and completeness, thus enhancing rigor, the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) statement was followed (Moher et al. 2009).

Part four and the final part of the literature review is a scoping review of risk and the media. A scoping review rather than a structured review was undertaken because a broad understanding of the role of the media in risk reporting was required. It was also apparent that there were a limited number of empirical studies within this realm therefore an exploration of what was available was most appropriate.

The scoping reviews were iterative in nature beginning from the development of the initial study proposal, through to the development of the research questions, the methodology and interpretation of the research findings. As the study evolved and a deeper understanding was gained, frequent returning to the literature review enabled rethinking, refining and reworking of this scoping review (Levac et al. 2010). As more of a systematic approach was taken for the structured reviews, the searches were conducted at a specific point in time and were more systematic than the scoping reviews in terms of following the PRISMA statement, therefore they could not be conducted as an iterative process. However, further searches of the literature in relation to risk perceptions towards *C.difficile* and healthcare associated infections were undertaken to capture any work published after the structured reviews were conducted to aid further exploration in the discussion chapter.

Part five presents concluding remarks from the literature reviews in terms of what is already known and what the gaps are and concludes by setting out the research aims and questions in order to address the gaps.

Part one: Approaches to studying risk perceptions and responses

Two major risk perception theories have dominated general risk perception research since the 1970s: the psychometric paradigm and Cultural Theory. More specific to risk perceptions and healthcare, the Health Belief Model (HBM), first developed in the 1950s is one of the most widely used theoretical frameworks. These theories provide a context in understanding factors that impact on how people perceive and respond to risk and are therefore useful springboards in generating ideas and concepts (Silverman 2011).

Psychometric paradigm

The psychometric paradigm was an influential model rooted within the disciplines of psychology and decision sciences (Abraham 2009). It was first developed in the 1970s to investigate lay perceptions of the risks towards nuclear power, natural hazards and chemicals (Slovic et al. 1982, Slovic et al. 1991). More recent risk research adopting this approach has explored a range of risk-related phenomena such as terrorism (Jenkin 2006), flooding (Siegrist and Gutscher 2006) and hurricanes (Peacock et al. 2005). The framework uses psychophysical scaling methods and multivariate analysis to produce quantitative representations of the way people judge a specific set of risks or hazards (Wählberg 2001, Dohle et al. 2010). The fundamental element of this approach is to isolate experts and public risk perceptions on the understanding that these two groups do not perceive or respond to risks in the same way.

While this model is helpful in acknowledging that people can understand and rate risks, there are a number of limitations which prevented it from being used more than as a springboard for ideas within this study. First, the paradigm assumes that all individuals assess hazards or risks in a quantifiable manner and ignores important social, cultural and institutional factors. As a result, it does not help to understand in any depth *how* and *why* people perceive risks and *why* risk perceptions differ among groups (Sjöberg et al. 2004). Furthermore, cognitive psychologists argue that individuals often make estimations and assumptions based on heuristic devices, such as mental guidelines to which knowledge about a risk is easily accessible, which this framework fails to capture in any depth (Boholm 1998). Sjöberg (2000) also point out that many studies using this approach are not explicit about the risk target or differences in personal and general risk ratings. For example, participants are only asked to rate the risk, with no further specification about the risk provided. Yet, research demonstrates that people process a range of social and contextual factors in order to judge them and also make varying estimations when they judge the risk to themselves, their family or others (Slovic 1987, Sjöberg 2000, Slovic and Weber 2002).

Cultural Theory

Based on the work of anthropologist Mary Douglas and political scientist Aaron Wildavsky (Douglas and Wildavsky 1982), Cultural Theory recognises that people's risk perceptions are the outcome of complex and diverse socio cultural processes and are not simply accepted as an unproblematic fact

(Douglas 1970, Oltegal et al. 2004, Taylor-Gooby 2008). This approach assumes that there are four specific viable ways of life defined by the strength of 'grid' and 'group' characteristics (Marris et al. 1998). A Grid-Group typology was developed as a tool to understand different logics of risk as they are expressed in particular social groups or organisations (Douglas 1970). For example, a specific culture will always correspond with a certain pattern of social relations which are unable to be combined in any other way. Grid-Group analysts can therefore deduce preferences, attitudes and behaviours for each ideal type in relation to various risk-related factors. These are characterised as hierarchists, egalitarians, fatalists and individualists.

Hierarchists (high group, high grid) have strong group boundaries. They generally have hierarchical views and great respect for authority (Pursglove 2010). As hierarchists favour rules and order, they are subject to both the control of other members in the group and the demands of socially imposed rules. These types of individuals believe that disease occurs when rules are broken, especially those derived from higher sources such as doctors (Tansey and O'Riordan 1999). Egalitarians (high group, low grid) have a powerful sense of social connectedness cemented by strong group boundaries and social patterning of self-expression (Grendstad 2003). They often exercise their control over one another by claiming to speak in the name of the group, which can lead to group disagreements (Langford 2002). Fatalists (low group, high grid) have a strong sense of social distinction and believe that their autonomy is controlled by their own interpretations of social institutions. They

see themselves as outsiders who are disconnected from these institutions and have little influence on events or people in their lives (Marris et al. 1998). They also tend to have the 'can't do anything about it' attitude towards health risks and that 'it will happen anyway'. For that reason, they often ignore health advice (Langford 2002). Finally, individualists (low group, low grid) are characterised by no group incorporation and no prescribed roles. They therefore feel less responsible for other members of the society. They regard the allocation of power and resources as their own responsibility, not influenced by power or status (Helman 2007). Consequently, they tend to blame themselves and their behaviour for ill health and have little respect for hierarchy and authority (Langford 2002).

Similar to the psychometric paradigm, although Cultural Theory provided useful insight into risk perceptions and responses, limitations are evident. First, it seems to be largely based on theoretical evidence, therefore its empirical substance is questioned (Sjöberg 2002a, Hirsch and Baxter 2011). Others have also argued that the four specific extremes to the grid-group typology inherently introduces a mobility hypothesis (Williamson and Weyman 2005). For example, elements such as personal and social identity and influences from various forms of social organisation can impact on people's beliefs and values, therefore positions may change over time due to various circumstances (Vandermoere 2008), yet the typology does not account for this. The lack of interaction between these groupings therefore creates a polarised perspective and fails to capture the reality of people's risk

perceptions and responses. Such a view seems to imply that there is a single perspective of risk, thus ignoring the fundamental concept that people are ambivalent and risk perceptions are socially constructed, fluid and subjective (Gaskell and Allum 2001).

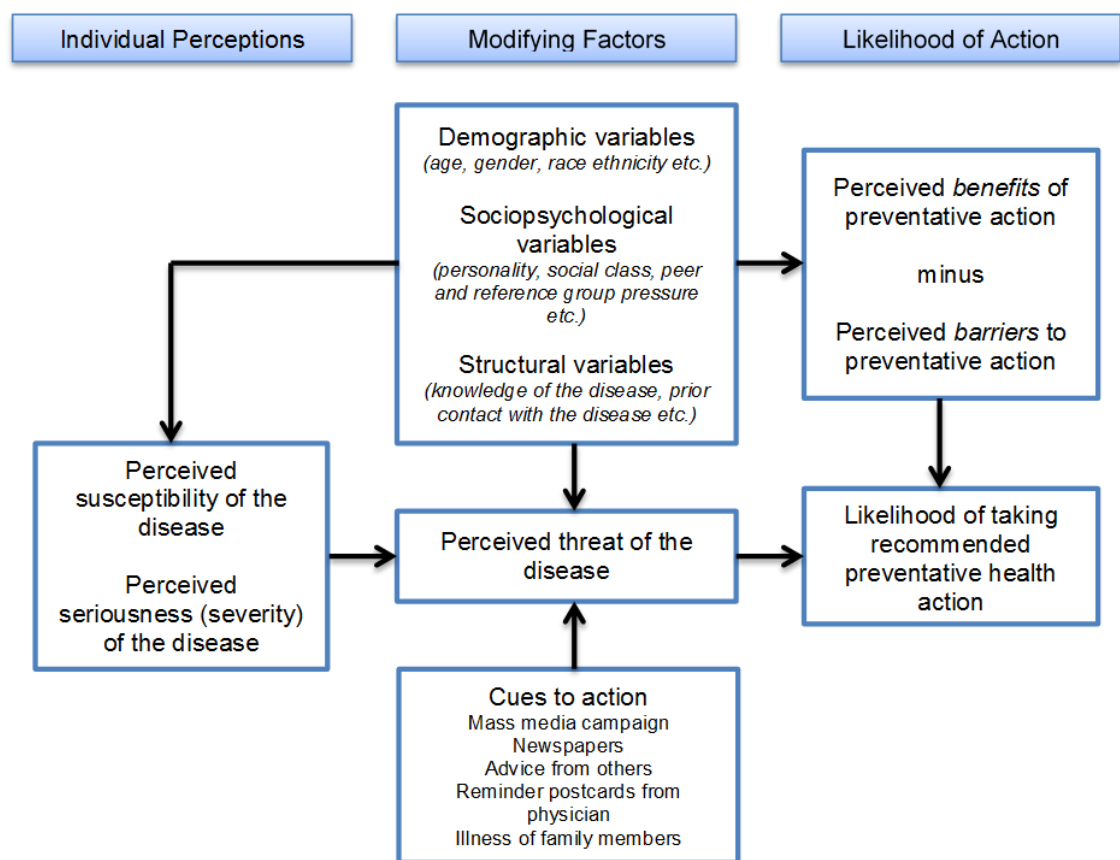
Health Belief Model

A number of social cognitive theories have been developed in order to explain, predict and change health-related behaviour. These include the Health Belief Model (HBM) (Janz and Becker 1984), Protection Motivation Theory (PMT) (Prentice-Dunn and Rogers 1986), the Theory of Planned Behaviour (TPB) (Ajzen 1991) and the Theory of Reasoned Action (TRA) (Fishbein and Ajzen 1975). Although all of these social cognitive theories use similar concepts, the HBM is the most dominant and widely used theory in health-related risk perception research (Kok et al. 2010, Flood et al. 2010, Setbon and Raude 2010, Masser et al. 2010, Bond and Nolan 2011). The HBM was first developed in the 1950s in response to the failure of a tuberculosis health screening programme (Hochbaum 1958). The overarching concept of the HBM is to distinguish personal beliefs and perceptions about a disease or health condition to enable in-depth understanding of how health behaviour can be determined or understood (Rosenstock 1974, Janz and Becker 1984).

Risk perceptions is a key determinant of the HBM as it derives from threat appraisal and is considered a major motivating factor in understanding preventative and protective health behaviours. The model comprises of six

main constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy. The links between each proposition of the model are illustrated in Figure 1.

Figure 1: Propositions of the Health Belief Model



Perceived susceptibility is concerned with people's perceptions about the likelihood of getting a disease or developing a health problem, and is believed to be one of the most powerful factors in the promotion of preventative health behaviour. The model hypothesises that the greater the perceived risk, the

more likely that the person will engage in preventative health behaviour (Bond and Nolan 2011).

Perceived severity relates to a person's perception of how serious a disease or health problem and its consequences are. It is hypothesised that if a person perceives the disease or health problem to have serious consequences, then they are more likely to take preventative or protective behaviour. An embedded element of perceived severity is also emotion, such as being fearful or worried about a health threat, therefore is an important consideration of the motivation to act (Chapin 2011).

Perceived benefits refers to a person's perception of the value or usefulness of adopting a preventative behaviour in decreasing the risk of developing the disease or health condition. This implies that people are unlikely to take precautions or act in a specific way if they do not think their actions will benefit them (Bayat et al. 2013).

Perceived barriers refers to the assessment and evaluation of obstacles that may be associated with adopting the preventative behaviour. In other words, if a person believes the obstacles or barriers to taking preventative action outweigh the perceived benefits, they are more likely not to take that action (Julinawati et al. 2013).

Cues to action are the presence of stimuli in the form of events, people, reminders or prompts that may influence a person to adopt preventative action. Often, when a person has little or no knowledge about something they tend to seek information, guidance and advice from others, such as family members, friends and peers. These social influences, especially from people who have had either direct or indirect experience of a disease or illness can initiate change in perceptions, therefore motivate a person to alter their behaviour (Orji et al. 2012).

Self-efficacy was a later addition to the HBM in 1988 to enable the understanding about a person's belief in their ability to make a health related change. It originated from social cognitive theory as one of the most important predictors for behaviour change whereby if a person has faith in his or her ability to do something, they are more likely to do it. Likewise, if they believe they do not have the capability to do something, they are less likely to make that change (Kaiser et al. 2013).

This model however, is not without its limitations. Munro et al. (2007) claim that there is insufficient clarity of the definitions for each component of the model. Furthermore, they state the relationships between variables are not made explicit. For example, they state that if perceived seriousness is high and perceived susceptibility is low, it is still assumed that the likelihood of action will be high. Yet, they argue that likelihood of action would be lower

than it would if both variables were high. Yarbrough and Braden (2000) further asserts that this also limits the applicability of the model to intervention studies.

Summing up

This section discussed the predominant risk perception theoretical perspectives that are used for risk perception research. Although the psychometric paradigm and Cultural Theory are widely used, they originated within anthropology and sociology and their applicability to health-related risk perception research is limited. Within the health-related risk literature, although a number of social cognitive theories have been developed, the HBM is the most widely used theory as it considers risk perceptions to be the central component in understanding responses towards a health-related threat. However, limitations of this model indicates that gaps in risk perception understanding remain. Nevertheless, these risk perception theories provided a structure for conceptualising risk perceptions from a broad sense and therefore were used as a platform to help guide this study.

Part two: Risk and risk perceptions

The purpose of this scoping review was to gain a broad understanding of what factors are known to be important in influencing risk perceptions and responses and how they might differ between public and experts. The review was guided by the following broad questions:

- What factors are important in understanding risk perceptions and how people respond to risk?
- What is known about the similarities and differences of risk perceptions and responses among the public and experts?

A search was undertaken using key words such as “risk”, “risk perceptions”, “risk response”, “health”, “healthcare”, “public”, “patients”, “experts”, “nurses”, “doctors” and “allied health”. These key words were searched individually and/or in combination using Boolean operator. Databases searched were: CINAHL, CINAHL Plus (EBSCO), Medline (EBSCO), PubMed, Science Direct (Elsevier), Embase, Zetoc, PsychInfo, Web of Science, OVID, SCOPUS, Applied Social Science Index and Abstracts (ASSIA). Additionally, content tables of a range of relevant journals were searched. These included Health, Risk and Society, Journal of Risk Research, Risk Analysis and International Journal of Disaster Risk Science. Further searches were conducted to capture material not located through the above methods. These included searching government body and professional organisation websites such as Health Protection Scotland (HPS), Centres for Disease Control and Prevention

(CDC), Public Health England, World Health Organisation (WHO), Royal College of Nursing (RCN) and The Kings Fund. Grey literature was also sourced to enable access to specific issues such as media impact on risk perceptions and responses. Key professional personnel were also 'followed' on social media sites, in particular Twitter, to enable access to further relevant literature. Only literature written in the English language was used and no other restrictions or filters were applied.

Any literature which was considered relevant was entered into NVivo 9 to allow for storing, indexing, memoing and organisation of themes. As the process of reviewing the literature evolved, it became clear that for people to be able to form perceptions about a risk and respond to a risk, they need to be in possession of some degree of information about that risk (Wray et al. 2006). In other words, people cannot make any evaluations or judgements about something they do not know exists. How people come to know about a risk, make evaluations and respond to a risk is initially shaped by the information they receive, who they receive it from and the way in which they receive it (May 2005). Initial evaluations or judgements are then shaped and responses to risk are based on understanding and experienced within psychological, social and cultural contexts (Joffe 2003). This is reinforced by Hampel (2006), who asserts that any risk issues that are of human value require value judgements which cannot be done in an objective way. In other words, people do not form risk perceptions about something or respond to a risk in isolation of the world

around them, rather it occurs through interaction with the social world and are context and situation specific (Renn 2004, Frewer 2004).

Risk perceptions and responses are therefore not regarded as an objective entity, but are socially and contextually constructed and determined. Taking this conceptual understanding into consideration, this scoping literature review:

- Discusses the concept of risk and its relation to probabilities and perception
- Examines important issues around risk communication
- Examines factors that influence risk perceptions and responses
- Explores the relationship between risk perceptions and risk responses

Risk

Historically, risk was attributed to gambling and was seen as a neutral measurable construct. Thus it was attributed to the probability or the mathematical likelihood of an event occurring, in addition to the consideration of the magnitude of the losses or gains that would ensue (Jacobs 2000). As time passed however, the 'gains' from a risk related event was eventually sidelined, and according to (Douglas 1992, p.3) it was "*pre-empted to mean bad risk*".

A major criticism of this early 17th century assumption is that risk was not viewed as being objective or independent of people's minds and cultures, therefore risk perceptions could not be easily quantified (Boholm 1998). As such, Slovic and Weber (2002) points out that objective characterisation of the distribution of possible outcomes are viewed as misleading. Furthermore, this early assumption of risk fails to embody the social and cultural context of *how* and *why* people come to understand risk (Taylor-Gooby 2004). How and why objects and practices become defined as a risk by individuals and/or groups of individuals was of particular interest early theorists, as highlighted by Douglas and Wildavsky (1982, p.5):

"No person can know more than a fraction of the dangers that abound. To believe otherwise is to believe that we know (or can know) everything. Yet even if we did, it would still be necessary for us to agree on a ranking of risks. In the absence of complete knowledge, and in the presence of disagreement between scientists and layman alike, how can anyone choose to zero in on any particular set of dangers? How, faced with endless possibilities, can anyone calculate the probabilities of harm (the risks)?"

Some years later, when German sociologist Ulrich Beck published 'Risk Society', he stated that the notion of risk was becoming increasingly central to the global society (Beck 1992). With that, he rejected postmodernism in favour of Risk Society by replacing the older industrial society, holding the view that

risks are a consequence of the reflexive modernisation process. However, Beck (1992) did not argue that the modern world was any more risky than previous eras *per se*. Rather his argument was that the nature of the risks were changing and so people's perceptions of risks were also changing.

Such views were also shared by British sociologist Anthony Giddens who was of the opinion that modern individuals were exposed to more 'manufacturer uncertainties' (Giddens 1991). He asserted that rather than being faced with natural risks, such as natural disasters, modern risks are considered to be manufactured i.e. generated by society. In this sense, later modernity was seen to be a 'risk culture'. However, Beck believed that increased reflexivity was the outcome of a higher number of risks occurring. Giddens on the other hand, argued that this was due to people's subjectivity being more sensitive to risks. Nevertheless, Beck and Giddens agreed that risk-induced systematic and often irreversible harm is based upon risk calculations and interpretation by individuals rather than of the risks themselves. Thus, it was thought to be necessary to separate the notion of risk from hazard or danger. As a consequence, risks could be changed, magnified, dramatised or minimised within knowledge, opening them up to social definition or construction. This, according to Beck was highly influenced by the media (Cottle 1998). The views of these theorists help us to understand that as modernisation progresses and new knowledge is created, the nature of risks will continue to evolve and as such, risk perceptions will also evolve because they are constructed, contextually interactional and fluid.

While the risk culture will continue to evolve, Holton (2004) reminds us that regardless of specific risk situations and contexts, there are two important factors present that will always remain important. First, people have got to care about the outcomes of a risk for it to affect them. The second factor is uncertainty. For people who care about what might happen if exposed to a risk, they often do not know what will happen if they are exposed. From this, Holton (2004, p.22) simply describes risk as “*exposure to a proposition of which one is uncertain*”. To illustrate this, he points out that if a man jumps from an airplane without a parachute, he is certain to die. He therefore faces no risk because risk requires both exposure *and* uncertainty.

Probability or perception?

It is widely acknowledged that a risk cannot be condensed into a single, well defined meaning as it means different things to different people. Additionally, understanding about risks are learned by socially and contextually structured conceptions and evaluations of the world (Sjöberg et al. 2004). It is generally accepted that risk perceptions are rarely found to be equal for experts and the public (Sjöberg 1999). However, one of the most discussed and debated issue within the literature is the apparent mismatch between expert and public risk perceptions. This is therefore thought to negatively impact on corresponding responses, thus giving rise to fundamental practice and policy management and communication challenges (Bostrom 1997, Fischhoff et al. 1982, Slovic et al. 1982, Sjöberg 1999, Sjöberg et al. 2004, Siegrist et al. 2007b).

Expert risk perceptions are believed to be more veridical than those of the public because it is assumed experts are more knowledgeable due to the perceived reliable scientific information they draw upon (Rowe and Wright 2001, Botterill and Mazur 2004). As such, predictions made by experts about risks are often based on scientific probabilities and are therefore viewed as a more robust measurement than purely uninformed judgements (Sjöberg et al. 2004). However, Powell (2007) argued that expert risk perceptions and responses based on scientific judgements are perhaps marginalised because the generalisations made often do not account for specific and individual circumstances. As a result, risk management and communication strategies based purely on scientific risk estimates may often result in a less favourable response by the public (Frewer 2004).

The public on the other hand, are generally found to be more concerned with consequences of a risk rather than the probability, particularly when they involve negative outcomes (Sjöberg 1999). Thus, even if the probability of a health-related risk occurring is low, the public may still be worried about it if there is the belief of potential severe personal outcomes (Kuo et al. 2011). For example, in a study exploring risk perceptions of avian influenza, members of the public in Europe who were considered to be at low risk of becoming infected reported high levels of worry and 'irrational' risk perceptions due to their beliefs about what would happen to them if they became infected (de Zwart et al. 2007). According to Gaskell et al. (2004), such perceptions of a risk are often dismissed by experts as the product of irrational beliefs

predisposed by uncertainty and having limited knowledge. It is asserted that this is due to socially influenced fear (Jackson et al. 2006, Pursglove 2010) and for being influenced or manipulated by the media (Blok et al. 2008).

This public-expert discrepancy can be exemplified by a retrospective study by Tuveri et al. (2009). Using a survey questionnaire, they explored differences of risk perceptions between patients and physicians regarding a laparoscopic cholecystectomy (LC) and an open cholecystectomy (OC). A sample of 207 patients who had undergone a LC and 19 physicians who had been responsible for providing information to patients about their LC were selected for the study. They found that patients' perceived risk of converting from a LC to an OC was significantly higher than the risk that was communicated by their physicians. The risks of surgical complications were also perceived significantly higher by patients than what was communicated by their physicians. Tuveri et al. (2009) suggested that a reason for this may be due to patients selectively recalling and emphasising the favourable outcomes of the LC, such as lower post-operative pain and shorter recovery time when the physician provided them with the information. Additionally, the authors claimed that over-estimating the impact of post-operative complications of the OC was likely to be the result of the stress of uncertainty that the patients had reported.

The characteristics of the participants identified for this study were limited, with only age, gender and education level explored. However, it was found that

younger and higher educated patient's perceived significantly higher risk of surgical complications than older and less well educated patients. Tuveri et al. (2009) postulated that this could be due to higher educated individuals wishing to know in greater detail all possible risks associated with the surgical procedure. They also found that the younger patients believed the psychological support during informed consent was of great importance, but less so for the older patients. However, patients stated that the impact of treatment on quality of life was not comprehensively discussed. In contrast, physicians all reported to have had sufficient discussions of this with patients.

Tuveri et al. (2009) concluded that the overall discrepancies between the physician and patients risk perceptions could be a result of a failure between patient and physician communication. Given that this was a retrospective study, there was a lack of control of variables that could have had an impact on patient and physicians outcomes. Additionally, the authors did not disclose how long after the procedure data was collected from participants. Recall of events and information by participants may have been challenging if some time had lapsed, thus could have impacted on responses given. Nevertheless, this study demonstrated discrepancies between the information physicians stated they provided compared to the information patients stated that they received, which subsequently impacted on how patients perceived risks related to their surgical procedure.

While recognising the importance of understanding expert and public risk perceptions, Eiser (2004) cautions against assuming that there are fundamental differences in the way risks are perceived by the public on the one hand and experts on the other. Given the socially constructed nature of risk perceptions, regardless of whether a person is an expert or a member of the public, Eiser (2004) argues that people generally will take on different roles at different times in order to balance benefits and costs for themselves and for those who are dependent on them. Sjöberg (1999) agreed and stated that the socialisation of values in a professional capacity, conformity pressures and vested economic and career interests are likely to impact on expert risk perceptions. Eiser (2004) further emphasises that most risk perception research which reports differences between these two groups of people often simply conclude that better communication is needed to reduce discrepancies. However, this is usually advocates by shifting seemingly irrational risk perceptions of the public more to the rational perceptions of the experts. This, Eiser (2004) asserts, merely aims to manipulate public opinion so that it is brought into line with experts, even when it is known that experts are not omniscient. He points out that it is more important and relevant to gain an understanding of the underlying factors in which different groups of individuals perceive risks rather than just the differences of what they perceive.

Factors that influence risk perceptions and responses

According to Sjöberg et al, (2004), the essence of individuals' risk perceptions is bound by the perceived probability of an adverse event and the magnitude

of its consequences. However, risk perceptions are multidimensional as they also include underlying value systems, social and physical circumstances and organisational factors (Slovic 2000). As a risk will mean different things to different people, Slovic et al. (1982) points out that a range of varied and complex cognitive processes are undertaken to evaluate uncertain situations and estimate the likelihood of expected outcomes. For example, individuals have varying estimations of risk when they rate risks to themselves, their friends or family or to the general population. In this sense, optimism bias is commonly reported whereby people may have realistic perceptions about a particular risk or threat to other people, but will often play down or underestimate the risk to themselves (Eiser 2004).

Another important consideration is that risk perception factors can also, and often do compete with each other. Measles, mumps and rubella (MMR) vaccination is a good example of this. The severity and the consequences of MMR are widely communicated, as is the importance of immunisation. However, it is reported that because vaccines are man-made, carry some degree of risk and are imposed upon people, they often create significant public fear. Therefore, perceptions of the consequences of the immunisation often outweigh perceptions of the consequences of the diseases, as the probability of a negative outcome from the risk itself may be ignored (Botterill and Mazur 2004). It is for this reason, studies continue to report high rates of MMR immunisation refusal among parents (Bond and Nolan 2011).

As established earlier, the public are often criticised for irrational risk perceptions and responses merely because they do not often align with those of experts (Eiser 2004). However, Powell et al. (2007) point out that accusations of irrational risk perceptions and responses are unfair and that just because an individual's risk perceptions does not align with others, they should not be necessarily be considered wrong or irrational. Differing views of risk may be based upon rational but alternative assessments, which are often influenced by direct or indirect experiences. This then may influence if and how individuals engage with risk management and communication strategies (Timmermans 2005). Therefore, it is fundamental to understand and consider factors that influence the way people perceive and respond to risk so that engagement with risk management and communication strategies can be maximised.

There is a body of literature which focuses on factors responsible for influencing individuals' risk perceptions and responses towards wider risks such as environmental, technological and other health related risks (Sjöberg 2000). Despite the variation of context, such wider knowledge is important in locating a conceptual understanding of risk perceptions and responses to inform future context specific research. The following section will draw on wider literature to highlight some of these influencing factors.

Uncertainty

Uncertainty plays a major role in how people perceive risk, particularly around ambiguous, complex or unpredictable situations or when individuals feel insecure in their own or others' state of knowledge (Brashers 2001). As such, uncertainty can have a significant impact on how people respond to a risk, for example heightening fear, anger, anxiety and upset (Powell et al. 2007). Through uncertainty, individuals construct their own reality, assessing, evaluating and responding to risk issues in accordance with their subjective perceptions. Therefore the perceptions they form are underpinned by the information available to them at that time, the source of risk information and how this information is processed and interpreted (Renn 2004). Sjöberg et al. (2004) assert that the concept of uncertainty is the assumption that an individual has a perceived lack of knowledge or understanding about something and that if a person's knowledge about a risk is complete that person would have no uncertainty. Indeed Eiser (2004, p.4) argues "*everything that is important about risk arises from actual or perceived uncertainty*". This, is connected to the uncertainty of the likelihood of events occurring, outcomes of events and what that means to an individual in terms of decision making:

"If we felt that there was nothing we could ever do to affect what might happen to us, we would have no decisions to take and there would be no point in worrying about the likelihood or value of future events. However, most of the time life isn't like that. We have choices to make, and these choices can have consequences for ourselves and others. It

is because these consequences are uncertain, and may leave us better or worse off, that we talk about risk” (Eiser 2004, p.8).

Particular attention seems to be mainly focused around the uncertainty of the public in risk perception literature, especially around the lack of technical knowledge of a risk (Smith 2006, Brewer et al. 2007, Brug et al. 2009, van der Weerd et al. 2011). Not surprising, researchers therefore often seem to advocate the need for more information and education in order to increase knowledge and reduce uncertainty (Brinsley-Rainisch et al. 2007, Easton et al. 2009). However, as already established, expert or official risk information is often communicated to the public based on scientific factors. This is largely an attempt to increase knowledge to counteract seemingly irrational perceptions, change perception and/or to persuade them to respond or act in a particular way (Frewer 2004). This way of providing and communicating risk information is sometimes referred to as the deficit model, which according to Botterill and Mazur (2004) has been the most predominant approach to risk communication since the early 1980s. Yet, this approach takes little or no cognisance of what public views and beliefs are and what factors influence these views. If information provided to the public goes against already established perceptions, then risk messages are likely to be distrusted or dismissed and rejected or ignored (Engdahl and Lidskog 2012).

Moreover, such a risk communication model seems to be based on the assumption that experts are knowledgeable and possess no uncertainty. Yet

this is surprising considering it is widely acknowledged that scientists, experts and policy makers frequently disagree with each other about specific health risks and what action needs to be taken in order to prevent harm (Sjöberg 1999, McKibbin et al. 2007). However, contrary to opinion that experts largely assess risk in objective measurable probabilities (Botterill and Mazur 2004), Skjong et al, (2001) argues that depending on what information and data are available and how this is processed, experts actually exhibit the same types of subjective biases as the public. These biases and uncertainty are therefore likely to cause variation in risk-related responses such as decision making and information provision, thus potentially invoking further uncertainty among the public. As such, continued accusations that public uncertainty is often caused by other risk communicators rather than experts, for example, the media, could be called into question (May 2005).

A study conducted by Bar-Dayana et al. (2010) provides some evidence of suggesting why variation among healthcare workers' responses to a health-related risk occurs. Their aim was to examine the relationship between the source of information about A/H1N1 pandemic and the willingness of healthcare workers to risk their lives to care for a patient with a fatal A/H1N1 flu during a pandemic. They hypothesised that using professional sources of information would positively relate to the willingness of healthcare workers to risk their lives for a patient if a fatal transformation of A/H1N1 virus occurred. The results from a survey questionnaire found that the most common sources of information were television, speaking with colleagues, reading Government

regulations, the internet and reading newspapers. Surprisingly, one of the least favourable sources of information was scientific articles. Those who did gain information from scientific articles were statistically more likely to risk their lives for a patient compared with healthcare workers who gained information from other sources. Additionally, those who were acquainted with the Government regulations around A/H1N1 were also significantly more willing to risk their lives for a patient compared. Consulting colleagues was also positively related to willingness to risk one's life for a patient.

The study also demonstrated the differences between healthcare professionals in their response to a risk issue, in that they were either willing or not willing to risk their lives to care for an infected patient (Bar-Dayana et al. 2010). This, they found was related to particular sources of information, in that the more the sourced information was perceived scientific and credible, the more likely it would influence positive behaviour (willingness to care for a patient). It could also be argued from these findings that those who were not willing to risk their lives were more uncertain about exposure and outcomes *because of* the information sources they used i.e. television, internet and newspapers. It was therefore presumed that those who sought information from more credible sources were provided with the most accurate information so that they could make an informed decision about treating a patient or not. Such information was therefore likely to reduce uncertainty about potential outcomes related to exposure of the risk. The study illustrates that the impact

of information sources on how individuals respond to risk related events thus has important implications for risk communicators.

While uncertainty is commonly assigned to an individual's perception of being uncertain themselves, Powell et al., (2007, p.324) assert that the notion of "*not knowing*" in a wider context is also important. In this sense they define "*not knowing*" as not only one's own knowledge but also of others' knowledge, the state of knowledge "*out there*" in the world or a combination of these. For example, in addition to an individual questioning their own knowledge about a health-related risk, they may also question their health practitioner's knowledge about it. As a result, doubts may be cast upon the advice and information with which they are provided. Additionally, Lidskog (2011) argues that it is not the information alone that is assessed, evaluated or accepted/rejected by individuals, but rather the extent to which the expert or institution providing the information is deemed to be trustworthy. The most common reasons for risk communicators to be distrusted by others limited, inconsistent or contradictory risk information provided (Viklund 2003, Blanchard et al. 2005, Gooby-Taylor and Zinn 2006, López-Navarro et al. 2013) or the information that contradicts any preconceived perceptions (Sjöberg 2001, Scammell et al. 2006).

A primary determinant of trust is an individual's perceived confidence that a person or an organisation can manage and communicate about risks effectively (Ferguson et al. 2009). The way in which confidence is perceived

by people can not only affect judgements of risks and benefits, but can also influence the acceptance of information and recommended risk management measures (Thornton 2003, Siegrist et al. 2007a, van der Weerd et al. 2011). Similarly, when people lack trust in someone or something, they are more likely to distrust and question the information provided to them, and are therefore unlikely to accept this information (Slovic 1993, Langford et al. 2000, Poortinga and Pidgeon 2003, Williamson and Weyman 2005, Scammell et al. 2006, Ferguson et al. 2009). Viklund (2003) further adds that individuals tend to trust people they know or have had positive personal contact with, which is why the public place more trust in information from friends, family and colleagues rather than from expert organisations.

From a theoretical perspective, trust in risk information communicators, according to Renn and Levine (1991, p.179) is sub structured into five core elements, all of which need to be present to achieve complete trust:

- Perceived competence (degree of technical expertise assigned to a message or source)
- Objectivity (lack of biases in information as perceived by others)
- Fairness (acknowledgement and adequate representation of all relevant points of view)
- Consistency (predictability of arguments and behaviour based on past experience and previous communication efforts)

- Faith (perception of 'good will' in composing information)

In order to gain absolute trust in the information risk communicators provide, all of these factors need to be present. Any slight deviation from any one of these could potentially have a significant negative impact on how trustworthy they are perceived, thus whether information is subsequently accepted (or rejected) in the future (Poortinga and Pidgeon 2003, Johnson 2003).

Heuristics

When individuals are faced with uncertainty about a risk, and do not have all the information relevant to that risk, cognitive shortcuts are used to make evaluations and judgements about it. This is otherwise known as heuristics: a common set of principles using simple mental strategies estimating probabilities to support judgement (Tversky and Kahneman 1974). Through the application of heuristics, individuals are able to reduce the complexity and difficulty of assessing probabilities connected to the risk into manageable judgements (Botterill and Mazur 2004). However, using heuristics can also lead to different interpretations or judgements about a risk because only partial information may be available or a person has been unable to process all available information (Slovic et al. 2004, Keller et al. 2006). Thus, it is this type of subjective assessment, that often leads experts to account for irrational or biased risk assessments of the public (Jackson et al. 2006). However, Tversky and Kahneman (1974) insist that the use of heuristics is not only

confined to the general public, and that experts can also be influenced by heuristics.

Although in many situations, individuals' mental shortcuts quickly help make good judgements and decisions in everyday life, sometimes, systematic errors and biases can occur (Epley and Gilovich 2006, Gigerenzer and Gaissmaier 2011). For example, people often act in a way that is comfortable for them and ignore advice given to them to prevent illness. Additionally, information may be overlooked or ignored because it may not align with their current beliefs. Understanding how heuristics are used for shaping risk perceptions and the biases that transpire from them can result in improved judgements and decisions in situations of uncertainty, thus this understanding is vital for risk management and communication (Tversky and Kahneman 1974).

There are two main types of heuristics most commonly found within risk perception literature: representativeness heuristics and availability heuristics (Slovic and Peters 2006, Pachur et al. 2012). Representativeness heuristics allows individuals to make associations about a risk based on a stereotype, schema or other pre-existing knowledge structure. For example, Peters et al. (2006) found that people may have a typical stereotype of a cancer survivor with images of chemotherapy side effects such as hair loss and uncontrollable nausea and vomiting. This, they argue can have a detrimental effect on how people may behave if a cancer patient does not fit into this perceived stereotypical category in that they may fail to receive the support they need to

maintain and improve their health. In another study, McDowell et al. (2013) explored how a family history of prostate cancer, risk perceptions and heuristic decision strategies influenced prostate cancer screening behaviour. They found that men who had a family history of prostate cancer saw their relative as a representative of the type of person who can develop prostate cancer and therefore judgements of vulnerability to the disease were similar to that of their relative. Similarly, men who had a friend or knew someone with prostate cancer used this persona as a referent. The authors suggested that such heuristics could be a positive influence on reported intention to be screened. However, the study was retrospective and the majority of men had already had a prostate screening, therefore the reasons for instigating prostate cancer screening behaviours could not be determined. Nevertheless, this study gained insight into how representativeness heuristics can shape risk perceptions.

Availability heuristics on the other hand, occurs when individuals can easily bring to mind exemplars or associations with a risk, often through the recollection of direct or indirect experiences and through social influences (Tversky and Kahneman 1973). Availability heuristics can be personally beneficial in terms of having an overall readily available impression of a risk rather than having to weigh up pros and cons of something based on often complex and incomplete information (Slovic et al. 2004). However Sunstein (2004) argues that because a risk is both vivid and salient, availability heuristic can also be the source of people's heightened fears about certain risks.

Additionally a person's memory can be biased so that a risk situation or event that is easily recalled can be perceived as more probable and serious than it actually is (Botterill and Mazur 2004), thus creating clear challenges for risk managers and communicators.

Undoubtedly, one of the biggest key players in bringing certain risks or associations to mind is the media. According to Pachur et al. (2012), consistent and continuous representation about a single health-related risk can give the impression that a one-off risk event is even more probable than expected. Baumeister et al. (2001) further add that bad news events which are usually more favourable to the media are far more powerful in availability heuristics than good news events, because they are often more memorable and easier to recall. Overestimations of risk situations can however, cause unwarranted fear and the adoption of unnecessary precautions. For example, while terrorist attacks in the UK may be rare and the number of people killed by terrorist attacks is relatively low, Goodwin et al. (2005) found that excessively high levels of anxiety are reported. Given that terrorist attacks generate considerable media attention, this could provide a plausible explanation of this heightened fear.

Familiarity

Unsurprisingly, people generally feel safer in an environment that is familiar to them. Risk perceptions operate in a similar manner, in that the more familiar a person is of a risk, the more likely they are to accept it and not be overly

concerned (Slovic et al, 2000; Barenness et al, 2010). As a consequence, Schmidt (2004) asserts that when individuals become more aware about and familiar of a risk, the notion of habituation occurs and the risk can become attenuated. This then causes people to exhibit optimism bias, believing they are less at risk of something than they really are (Clarke et al. 2000, Sjöberg 2000).

The implications of optimism bias in relation to risk-related behaviour are significant. Studies have found that because the risk is familiar and habituation occurs, people tend not to take protective measures or change behaviour (Klein et al. 2010). Furthermore, risk warnings can often be dismissed as exaggerated or unrealistic (Fielding et al. 2005). In contrast, those who do engage in protective behaviour may demonstrate unrealistic optimism towards the risk *because* they believe their behaviour has made a difference (Bränström et al. 2006).

This is demonstrated in a study by Liao et al., (2009), who explored public perceptions of H5N1 avian influenza previously affected by it. Data were generated from semi-structured interviews from participants in Vietnam, Hong Kong, Thailand and Guangzhou. Although limited detail was provided to make an accurate assessment of the rigor and trustworthiness of data analysis, findings revealed that while H5N1 was acknowledged as a 'new' disease by many participants, it was considered merely the re-emergence of old diseases they had experienced in the past. The belief was that these diseases were

inevitably cyclic and natural, with many respondents in all geographical areas admitting that they were readily accepted and caused little concern. Despite having received copious information about the disease and guidance on protective measures, this guidance was not considered of great importance therefore it was not adhered to as stringently as it should be. However, the methodology employed for their study restricted the depth of the investigation in terms of in-depth exploration around how and why people perceived what they did. Nevertheless, the study makes an important contribution in terms of demonstrating the potential relationship between familiarity and adherence to perceptions of risk and adoption of preventative measures. This therefore, has implications for future risk communication and management strategies.

Similar conclusions were made by Fielding et al. (2005) on the basis of their results following a quantitative telephone survey of 986 households in Hong Kong. They aimed to determine exposure and risk perception of avian influenza from sales of live chicken. The authors concluded that hazard exposure causes familiarity, therefore it reduces the concerns that people may have about a risk. As such they argue that because of this risk, warnings are likely to be dismissed as exaggerated or unrealistic. This study was limited in that the determinants of risk perceptions were based on a section of only four questions relating to perceived likelihood and probability of getting sick through contracting avian influenza from buying chickens and by identifying whether or not risk had been expressed to them from other people. However, similar to the above study by Liao et al. (2009), Fielding et al. (2005) also

reinforced the potential impact of risk information and guidance if they do not align with public views.

In contrast to familiar risks, unfamiliar or new risks often engender greater concern or fear because the consequences or outcomes are perceived to be more severe (Adeola 2007, de Zwart et al. 2009). This is often referred to as pessimism bias. Pessimism bias can also lead to people not taking preventative action because they do not see the benefits (Gaskell et al. 2004). It can also cause stigmatization towards those who are perceived as a possible source of the risk (Maunder et al. 2003, Brug et al. 2004).

Controllability

Having control over a risk reflects an individual's ability to prevent negative outcomes once the risk or hazard has been initiated. According to Slovic (2000), if an individual has control over exposure of a risk, the risk is deemed to be voluntary as they will choose whether or not they expose themselves to that risk. Unfamiliar risks are also perceived to be less controllable than more familiar risks (Gaskell et al. 2004).

Individuals generally tolerate or are more accepting of a risk if they voluntarily engage in a particular behaviour (Cook and Bellis 2001). Sjöberg et al., (2004) asserts that this is due to the level of control the individual believes they have on the situation. However, this perspective does not always result in a favourable response. For example, motor car drivers believe they are less at

risk of being involved in a car accident if they are the driver as opposed to the passenger because they have control over the vehicle. However, they will also often display an exaggerated sense of control because they hold the belief that they have greater control than the average person, presumably because they believe they are better drivers than others (Kos and Clarke 2001). Similarly in the context of healthcare, Weinstein et al., (2005) found that despite acknowledging the risks of developing cancer through smoking, smokers underestimated their own risk of developing cancer due to perceived personal control of being able to adopt other preventative strategies such as exercising or taking vitamins.

According to Nordgren et al., (2007), however, when exploring the role of controllability in relation to risk perceptions, many researchers make the mistake of simply asking how much control someone thinks they have over a risk. They argue that this concept is too ambiguous as it does not clearly define whether it relates to the command over exposure to the risk itself (volition) or the command one has over the outcome (control). Being able to differentiate between the two is important because these are distinct concepts that have opposing influences on risk perceptions. Volition refers to an individual having the mental capacity to act in a specific way while understanding potential consequences (Schwarzer et al. 2011). For example, a person may decide to drive while under the influence of alcohol but this would be on the understanding that such behaviour may result in a negative outcome. Such control over exposure tends to increase levels of concern

about the risk. Control over outcome however, enables individuals to adopt specific behaviour in order to control the outcome of the risk. Control from this perspective on the other hand tends to decrease levels of concern about the risk (Foster et al. 2008).

In terms of voluntary risks, individuals tend to believe that they are more in control of them than they actually are, thus linking to optimism bias (Sjöberg et al. 2004). Klein and Helweg-Larsen (2002) conducted a meta-analysis which found a strong association between optimism bias and controllability. The depth of findings and interpretation of this analysis enabled the separation of controllability into primary and secondary control and their association with different variables. Primary control was considered as direct action by the individual to change his or her situation or actions, thus it was the individual that took action and responsibility. Secondary control however, was an indirect or passive way of claiming control such as relying on other's actions, luck or fate. The analysis showed that younger adults attending college relied more on primary control in comparison to older, non-college adults. The reason for this they argue is that individuals generally lose their ability to use complete primary control as they get older therefore they rely more on secondary control. Furthermore, this analysis found that reliance on primary control was also attributed to culture due to US participants exhibiting a stronger association between optimism bias and control as compared to non-US participants. The authors stated this was likely to be due to the US being a capitalistic society which emphasises power and responsibility of the

individual and so personal responsibility and control is deeply ingrained in America culture.

Summing up

This scoping literature review has established that risk perceptions and responses to risk are complex and multi-dimensional. Although it is demonstrated that risk perceptions and responses are context specific, there are a range of broad factors that impact on them. These include uncertainty, heuristics, familiarity and controllability. This review also established that risk perceptions are thought to be different between experts and the general public due to the different risk estimations that are applied to different risk contexts. For example, expert judgements on risk are based on objective probability measurements whereas the public risk perceptions are subjective and socially constructed (Sjöberg et al. 2004). However, although public perceptions are often thought to be irrational because of their subjectivity, the literature asserts that this cannot be a reason for them to be dismissed. Rather, risk perceptions need to be considered when developing risk management and communication strategies or such strategies will likely be rejected or dismissed.

Beck (1992) questions how worried we should be about certain risks and who decides how worried we should be. He questions where the line is between prudent concerns and crippling fear and hysteria and who indeed defines this. He questions the predictions of scientists when their findings often contradict each other and who is responsible for changing their minds so fundamentally

as well as the integrity of politicians and the media when the former declare there are not risks, while the latter dramatises the risks. Thus, he argues that rather than living in a risk society *per se*, we now actually live in a risk *perception* society. Beck (1992) posited the view that risk is ambivalence and being at risk is the way of being and ruling in the world of modernity. Consequently, rather than taking risks at face value, it is their perception that should be the subject of exploration and investigation (Durodie 2005).

Having considered the broader risk perception literature and identified some important factors, the next part presents the findings of the structure literature reviews and identifies what is known about risk perceptions more specifically in relation to the public, patients and healthcare professionals around *C.difficile* and other healthcare associated infections.

Part three: Risk perceptions and responses in the context of C.difficile and healthcare associated infections

Public and patients

The review of this literature was conducted through two structured reviews. The first review aimed to understand factors that impact on public and patients risk perceptions and responses towards *C.difficile* and other healthcare associated infections (Burnett et al. 2012) and the second review to understand factors that impact on healthcare professionals' risk perceptions and responses towards *C.difficile* and other healthcare associated infections (Burnett et al. 2013b). On conducting an initial search for both reviews, it was quickly identified that there was very limited risk perception literature specific to *C.difficile*. It was for this reason that the search strategy for both included other healthcare associated infections to allow for a more substantial analysis of the literature without compromising the rigorous approach to the review.

The first structured literature review was guided by the following questions:

1. What factors impact on public and patients' risk perceptions and responses toward *C.difficile* and other health care-associated infections?
2. How do these risk perceptions and responses vary?

The online electronic databases searched via EBSCO Host were: Medline, CINAHL and PsycINFO. These were selected as they include literature from

the disciplines that most reflect the topic, such as nursing, medicine, allied health, sociology and psychology. Key search terms such as “risk perceptions”, “risk”, “opinion”, “*Clostridium difficile*”, “healthcare associated infections”, “infections”, “public” and “patients” were then applied. The search strings were combined using Boolean operator “AND”. No other search filters were applied. Reference lists of all identified literature were scrutinised, hand searches of infection prevention-related journals such as Journal of Infection Prevention, Hospital Infection Society and American Journal of Infection Control were undertaken, grey literature were searched and key web sites, such as Infection Prevention Society, Royal College of Nursing, Department of Health, Health Protection Scotland and NHS Education for Scotland were examined.

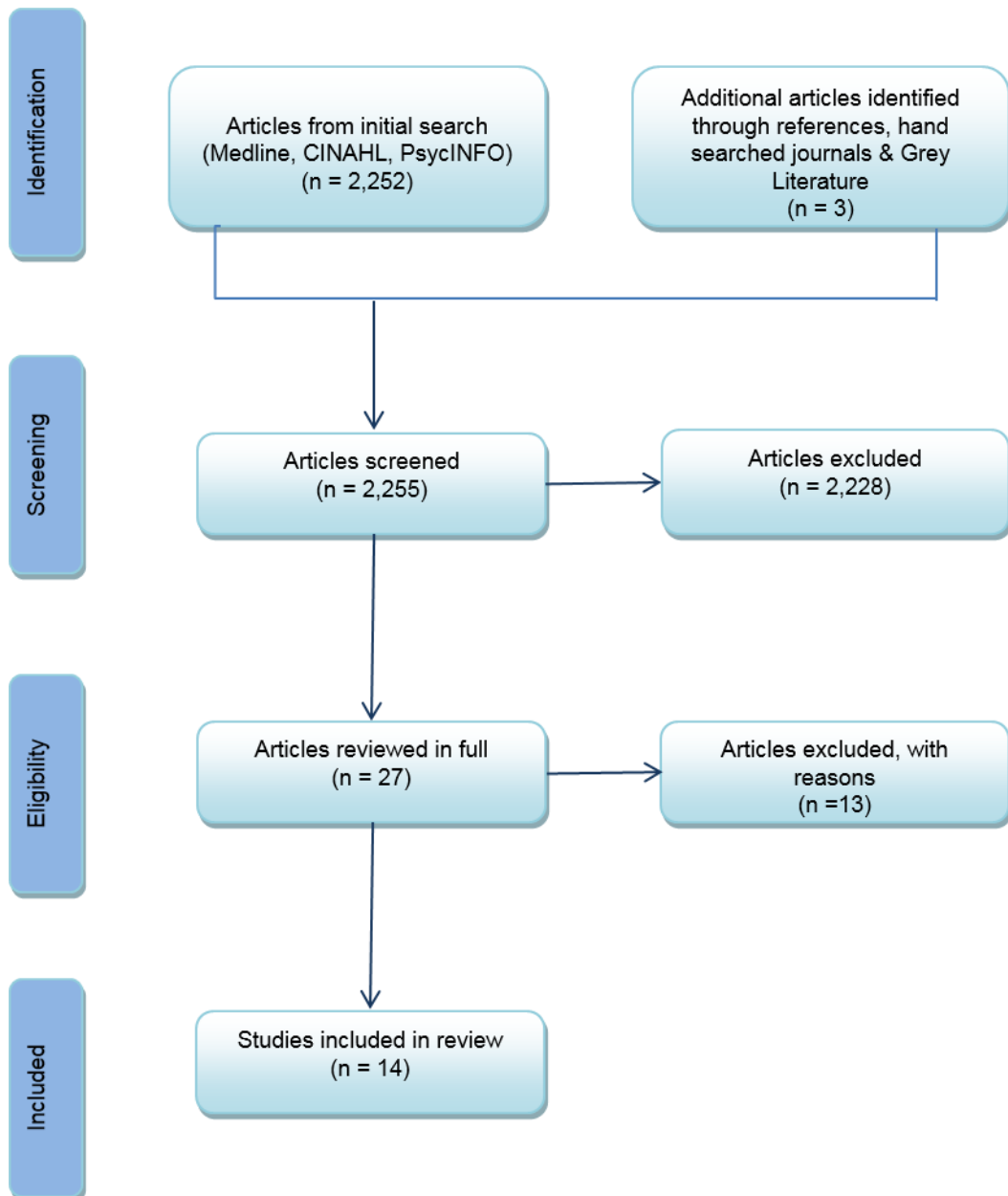
To ensure transparency and completeness of this review, the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) statement was used (Moher et al. 2009). Inclusion and exclusion criteria were applied to ensure only relevant literature were included in the review (Table 1). Titles and abstracts from the initial search were appraised and full articles obtained and appraised if they met the inclusion criteria.

Table 1: Inclusion and exclusion criteria (patient and public studies)

Inclusion	Exclusion
Empirical research	Discussion papers, editorials, reviews and/or commentaries
Participants who were members of the public or patients	Does not include patients or public
A focus on risk perceptions and/or responses towards <i>Clostridium difficile</i> and/or healthcare associated infections	Concerned with risk perceptions and/or responses on topics not related to <i>Clostridium difficile</i> and/or healthcare associated infections

Key information from each article was extracted onto a standardised form which included purpose, design and method, sample and setting, main findings pertaining to risk perceptions and responses and limitations (Appendix 1). Data was then entered into NVivo 9 for storing and indexing. Figure 2 presents the search strategy and PRISMA flow chart.

Figure 2: Search strategy and PRISMA flow chart



In total, 14 articles were included in the review. These comprised of 9 cross-sectional quantitative studies and five qualitative studies, all of which were conducted across an international spectrum. Only one study focussed on *C.difficile* with the rest relating to other healthcare associated infections.

Methodological quality assessment was undertaken using quality indicators developed by Hawker et al. (2002). No study was excluded on the basis of quality owing to limited understanding of this topic.

The only study relating to *C.difficile* was a small descriptive quantitative study exploring public perceptions and responses using a survey questionnaire (Collins et al. 2009). Of the 98 hospital out-patients who completed the survey, most stated they did not know what *C.difficile* was or how it was treated. Many however, did associate transmission with poor hygiene and direct contact with hospital staff and infected patients. Most participants admitted to being worried about contracting *C.difficile* while in hospital and stated they would feel angry or afraid if they did. Information sources about *C.difficile* were mainly newspapers and television. No exploration however, was conducted as to why or how these perceptions and responses were shaped. Additionally, no demographic characteristics were identified therefore no discussion relating to risk perceptions could be made.

With regards to healthcare associated infections, patients and public who perceived themselves to be at high risk of acquiring a healthcare associated infection while in hospital admitted to having little knowledge or understanding of infection (Newton et al. 2001, Hamour et al. 2003, Merle et al. 2005, Criddle and Potter 2006, Brinsley-Rainisch et al. 2007, Abbate 2008, Madeo and Shields 2008, Moore et al. 2010, Burnett et al. 2010). Even those with a good knowledge base, the public still believed themselves to be at high risk of

infection (McLaughlin et al. 2008). Many were afraid of the consequences of healthcare associated infection and related it to high morbidity and delayed discharge (Hamour et al. 2003, Mattner et al. 2006, McLaughlin et al. 2008, Moore et al. 2010, Burnett et al. 2010). Some also believed it was untreatable and could kill them (Hamour et al. 2003). Concerns over lack of, improper and exaggerated information provided by healthcare organisations and professionals were voiced (Miller and Farr 1989, Newton et al. 2001, Merle et al. 2005, Gill et al. 2006, Burnett et al. 2010). Media representation was implicated for influencing high risk perceptions in most studies (Hamour et al. 2003, Criddle and Potter 2006, McLaughlin et al. 2008, Brinsley-Rainisch et al. 2007, Madeo and Shields 2008, Moore et al. 2010, Burnett et al. 2010). However, little in-depth exploration of audience reception of media representation was undertaken. Some participants drew upon direct and indirect experiences of healthcare in order to make sense of their risk perceptions, such as poor staff hand hygiene and lack of use of gloves and aprons (Newton et al. 2001, Abbate 2008, Burnett et al. 2010). As such some stated they did not have a great deal of confidence in the NHS (Burnett et al. 2010) and that they would seek legal action if they acquired a healthcare associated infection (Merle et al. 2005).

Overall, this literature review highlighted patient and public risk perceptions and to a lesser degree how these individuals responded to risk. A number of studies made assumptions about the media impact on risk perceptions but they were largely unsupported by empirical evidence. Methodologically, the

quality and strength of findings were affected by small study populations and lack of depth to the inquiry with most studies simply concluding the need for further information. Additionally, with the lack of exploration around why people perceived what they did, little understanding was gained in terms of how and why risk perceptions and responses varied. This review found very little research specific to *C.difficile* and although the inclusion of wider studies provided insight into what some risk perceptions were, findings were limited.

Healthcare professionals

The second structured literature review was guided by the following questions:

1. What factors impact on healthcare professionals' risk perceptions and responses toward *C.difficile* and other health care-associated infections?
2. How do these risk perceptions and responses vary?

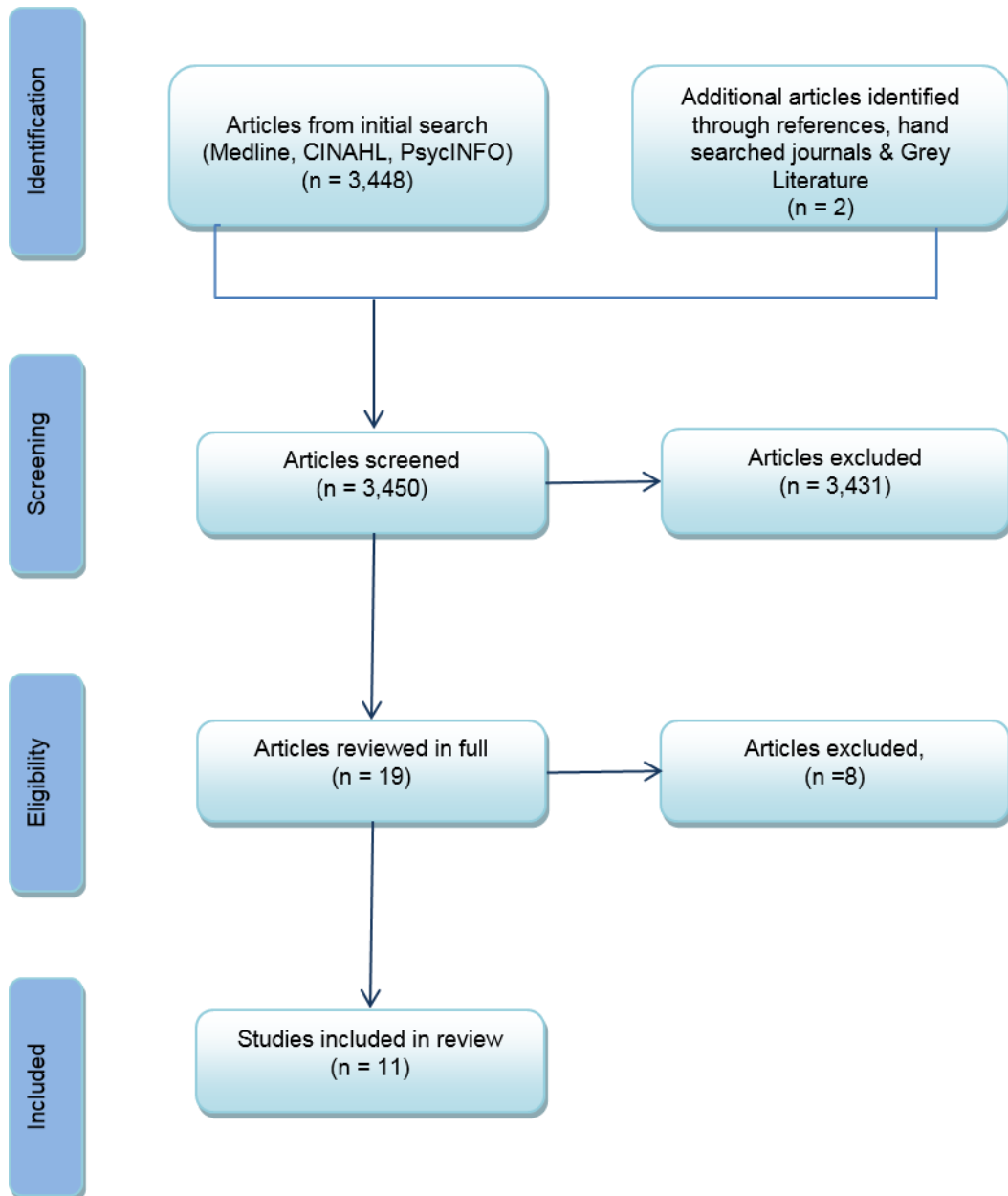
The same search strategy, study selection and data extraction process as the previous structured literature review was implemented for the purpose of this review, with the exception of search terms. For this review these included, "risk", "risk perceptions", "opinions", "*Clostridium difficile*", "healthcare associated infections", "infections", "healthcare professionals", "nurses", "medical staff" and "allied health professionals". Additionally, the inclusion and exclusion criteria differed (Table 2)

Table 2: Inclusion and exclusion criteria (healthcare professionals' studies)

Inclusion	Exclusion
Empirical research	Discussion papers, editorials, reviews and/or commentaries
Participants who were healthcare workers	Does not include healthcare workers
A focus on risk perceptions and/or responses towards <i>Clostridium difficile</i> and/or healthcare associated infections	Concerned with risk perceptions and/or responses on topics not related to <i>Clostridium difficile</i> and/or healthcare associated infections (including perceptions of practice)

Key information from each article was extracted onto a standardised form which included purpose, design and method, sample and setting, main findings pertaining to risk perceptions and responses and limitations (Appendix 2). Data was then entered into NVivo 9 for storing and indexing. Figure 3 presents the search strategy and PRISMA flow chart.

Figure 3: Search strategy and PRISMA flow chart



Of the 11 articles included in the review, six were cross-sectional survey quantitative studies, four qualitative studies and one mixed methods study, all of which were conducted across an international spectrum. Three studies focused on *C.difficile* with the remainder about MRSA. Methodological quality

assessment was undertaken using quality indicators developed by Hawker et al. (2002). No study was excluded on the basis of quality owing to limited understanding of this topic.

Studies focused on *C.difficile* found that there was a significant lack of knowledge and understanding about the technical issues of the infection which included microbiology, risk factors, diagnosis, treatment and prevention (Prieto and Clark 2005, Vaughan et al. 2006, Aroori et al. 2009, Tsagkaraki et al. 2009). One study found senior physicians and nursing staff knowledge to be poorer than it was in trainees (Aroori et al. 2009). Nurses and doctors also perceived healthcare associated infections to be serious and the probability of both patients and themselves acquiring an infection to be high (Prieto and Clark 2005). Additionally, they recognised that *C.difficile* infection could lead to serious illness or death (Tsagkaraki et al. 2009).

Nurses were reported as having a lack of confidence about the effectiveness of preventative measures such as hand hygiene and glove and apron use as well as confusion over the rationale for infection prevention practice (Prieto and Clark 2005). This appeared to be the result of a lack of policy detail and information provision. However, in another study, despite reports of received infection prevention education, knowledge remained poor and uncertainty persisted (Vaughan et al. 2006). Poor and unsafe infection prevention practice was observed by nurses in relation to hand hygiene and glove use (Prieto and Clark 2005). Additionally, poor practice was self-reported by doctors, nurses

and infection prevention link professionals. This was often rationalised by confusion of policy requirements, ritualistic behaviours and lack of resources (Vaughan et al. 2006). However, in all these studies a lack of demographic characteristics obtained prevented exploration of how risk perceptions and responses differed. Furthermore, little attention was given around factors that impacted on such risk perceptions and responses.

In terms of MRSA, a similar lack of knowledge and understanding was reported (Lines 2006, Gill et al. 2006, Trigg 2008, Wolf et al. 2008, Paudyal 2008, Morrow et al. 2011). Perceived risk of infection to self, varied across studies. In one study doctors, nurses, ancillary staff and volunteer workers perceived themselves to be at high risk (Kouabenan and Dubois 2007), yet in another study, nurses and domestics perceived themselves to be at a low risk, in comparison to doctor's high risk perceptions (Gill et al. 2006). It was suggested that this was due to the educational training they received, but no further explanation was offered. Those working full time and with more clinical experience tended to believe they were at low risk of acquiring MRSA (Kouabenan and Dubois 2007). The authors suggested that that may be been because those individuals were more familiar with and knowledgeable about MRSA due additional training they had received.

Some nurses stated that MRSA was often inevitable due to close interpersonal contact, understaffing, and lack of resources, which they had no control over therefore could not prevention infection occurring (Lines 2006). Additionally,

predisposing factors to infection included patients being permitted to 'wander about' and being unwilling to 'obey orders' about infection prevention measures (Wolf et al. 2008). One study reported that the more healthcare professionals thought the MRSA risk was probable for them, the less control they perceived they had over it (Kouabenan and Dubois 2007). Similar to the previous literature review, the media was a common source of information for healthcare professionals about healthcare associated infection (Gill et al. 2006, Trigg 2008). No exploration around media influence was conducted.

Summing up

These structured literature reviews established that current empirical research is limited. However, they provided a little more insight into risk perceptions of healthcare professionals compared to the public in that some exploration was given around what shaped these perceptions. The main findings appeared to be underpinned by perceptions of controllability whereby healthcare professionals questioned the effectiveness of preventative measures and believed that prevention was not often achievable owing to circumstances beyond their control. Similar to the previous review however, the quality and strength of findings were affected by small study populations and lack of depth to the inquiry. Additionally, most studies simply concluded the need for further information.

Part four: Reviewing the literature around risk and the media

There is little doubt that the media play a fundamental part in shaping risk perceptions and influencing responses to risk issues. However, owing to the complexity of how and why risk perceptions are shaped and responded to, it seems almost impossible to establish exactly to what extent the media are responsible (Hackett 2008). Yet despite this, the media are frequently criticised for creating fear and panic and influencing irrational perceptions and responses among the public through sensationalist, dramatic and inaccurate reporting of health-related risks (Hamour et al. 2003, Collins et al. 2009, Moore et al. 2010).

Kitzinger (2005) believes that to ritually scapegoat the media for misrepresenting risk issues miss-assigns blame, lets experts or scientists 'off the hook' in terms of not accepting responsibility and preserves the image of science as a distinct value-free activity which is misrepresented and distorted by journalists. Additionally when experts or scientists complain about media misrepresentation or distortion, they are inherently refusing to address the wider social and political implications of their work.

Rather than continuing to report empirically unsupported claims of media impact on risk perceptions and responses, or attempting to measure the extent of media influence on risk perceptions and responses, it appears to be more beneficial to understand how media engage with risk, how individuals make sense of media representation and to explore how this may affect responses.

This could then be used to identify better ways for healthcare organisations and professionals to engage with the media with regard to health-related risk reporting. Additionally, this understanding can allow pre-emptive risk management and communication to mitigate negative and inaccurate short and long term consequences (McCluskey and Swinnen 2011).

Undoubtedly, the interest of media influence on risk perceptions and responses has sparked the interest of researchers over recent years. However, Kitzinger (1999a) argued that many researchers have approached such studies too simplistically. For example, she comments that media coverage analyses are often accompanied by assumptions related to the role of the media and risk reporting without any exploration of audience reception or media production. In order to gain a wider and deeper understanding of the role of the media and health-related risk reporting, aligning to current theoretical and empirical work, three factors are important: content, reception and production (Kitzinger 1999a, Kitzinger 1999b, Henderson 1999, Philo 2007, Kitzinger 2009, Wardle and Boyce 2009).

The purpose of this scoping review therefore was to examine the literature around how risk is represented in the print media, how individuals make sense of media representation and what influences the production of health-related risk stories in the print media. It is acknowledged that the media includes a range of sources such as newspapers, magazines, television and the internet. However, given that newspapers are one of the biggest sources of news for

the public and that this study was not broad enough to encompass this wider range of media source, it was decided to focus on newspapers for this part of the study. The review was therefore guided by the following questions:

1. How are healthcare associated infections represented in the print media (content)?
2. How do readers make sense of and respond to risk issues in the media (reception)?
3. What factors impact on what is represented in the print media (production)?

A search was undertaken using key words such as “risk”, “risk perceptions”, “risk response”, “risk reporting”, “media”, “newspapers”, “journalists”, “media coverage”, “media representation”, “media production”, “media audience reception”, “healthcare associated infection” and “infection”. These key words were searched individually and/or in combination using Boolean operator. Databases searched were: CINAHL, CINAHL Plus (EBSCO), Medline (EBSCO), PubMed, Science Direct (Elsevier), Embase, Zetoc, PsychInfo, Web of Science, OVID, SCOPUS, Applied Social Science Index and Abstracts (ASSIA). In addition to database searches, content tables of a range of relevant journals were searched. These included Journal of Media and Cultural Studies, Journal of Media Practice, New Media and Society, Critical Studies in Media Communication, and Health, Risk and Society. Additional search strategies were adopted in order to capture material not located

through the above methods. These included searching specific websites such as Glasgow Media Group, Cardiff School of Journalism, Media & Cultural Studies, Health Protection Scotland, CDC, Public Health England, WHO, the Royal College of Nursing, and The King's Fund. Grey literature was also sourced in order to access specific issues such as media impact on risk perceptions and responses. Key professional personnel were also 'followed' via Twitter which enabled access to further relevant literature. Only literature written in the English language was obtained. No other restrictions or filters were applied. The relevant literature was entered into NVivo 9 to allow for storing, indexing, memoing and organisation of the literature.

Content

As media professionals can choose what they present as news and decide how they represent a risk and shape a story, they have a significant amount of power to shape risk perceptions and responses (Smith et al. 2002a). Thus they present concepts about what is and what is not acceptable, what is and what is not important (Gamson et al. 1992). In doing so, they employ rhetorical devices in order to make the news interesting and to emphasize dramatic and emotive elements or controversy. Smith et al. (2002a) argue that rather than simply reporting on the 'real world', they contribute to the creation and re-creation of this world. According to Hughes et al. (2008), framing is a selective way in which this is achieved. In other words, journalists amplify their stories about risk in order to classify and label them in a particular way and position them in a web of structure and associations.

In terms of the exploration of content, this review found no media coverage analysis specifically towards *C.difficile*. There were, however, a few studies located exploring how MRSA was represented in newspaper coverage ranging from 1990 - 2005. In order to gain an understanding with regards to wider healthcare associated infections, these were examined more closely for the purpose of this review.

Following an analysis of the drivers of UK media coverage of MRSA, Boyce et al. (2009) found that most story hooks were about victims of MRSA as opposed to science or objective data. According to Taylor and Sorenson (2002) this is not surprising as the emphasis on personal narratives are a popular choice for journalists owing to the element of human interest, which has the potential to garner attention, interest and evoke emotion. In doing so, Seale (2005) highlights that journalists choose to depict victimhood and highlight particular 'victims' who perhaps represent the reader or someone close to them who are at their most vulnerable. As a result, this personalisation of a newspaper story brings it to life so that readers can connect with it (Petts 2001).

Similar findings regarding the use of personal narratives were reported by Washer and Joffe (2006) on examining social representations of MRSA in British newspapers over a ten year period. Their analysis, however provided more detail about the type of 'victims' represented and potential explanations for such a heavy focus on such emotive personal stories. First, the majority of

tabloid newspapers focused on famous people who had contracted MRSA such as television actress Leslie Ash and former 'agony aunt' Claire Rayner, and details of their 'suffering' was made explicit. An additional focus within the coverage was a baby who, born healthy, was reported to have acquired MRSA and died at 36 hours old. What was also notable was that these personal stories, particularly the latter, dominated much of the coverage in the run up to the May 2005 general election. They became a cause celebre during the election campaign, which arguably then forced policy makers to make MRSA a priority for action. This would likely have generated increased interest in their stories.

In terms of the representation of MRSA as an infection, terminology such as 'killer superbug', 'doomsday scenario' and 'impending health crisis' were frequently used in favour of the correct scientific terms to describe it (Washer and Joffe 2006, Crawford et al. 2008). Additionally, battle and war metaphors were dominant in a number of stories, portraying MRSA as the enemy, attacking, invading and spreading relentlessly and individuals 'fighting germs' and 'combating infection' (Washer and Joffe 2006, Chan et al. 2010). Smith et al. (2002c) assert that the use of specific metaphors appears to be a common strategy employed by journalists to construct meaning and add negative connotations and associations, thus making news more interesting and dramatic.

Inherent within the representation of victimhood, according to Seale (2003), media coverage also often depicts 'villains' whereby blame is apportioned to something or someone. This was supported by Chan et al. (2010) following a newspaper coverage analysis examining the prominence of MRSA reporting in the UK press, particularly around hospital cleanliness, whereby the apportion of blame was of particular significance. Both tabloid and broadsheet newspapers reported about 'shoddy hygiene procedures', 'unclean hospitals' and 'appalling lack of hygiene' with one broadsheet headlining 'dusty wards blamed for killer bacteria'. Embedded within these stories was also a strong emphasis placed upon the apparent carelessness by healthcare staff towards infection and cleanliness. The authors postulated that the 'dirty hospital' frame was used as shorthand for blaming and accusing politicians and the NHS managers for not addressing the problem.

In contrast however, Washer and Joffe (2006) found that in their media coverage analysis of social representations of MRSA, it was the hospital staff that bore the brunt of the blame. Doctors were berated for their lack of training and lack of hygiene, and nurses were criticised for their sloppy general hygiene, lack of dedication and poor nursing care, especially around poor hand washing practices. However, in some coverage the responsibility for this was laid at the door of the NHS and politicians for causing such poor standards.

Similar to reports from Boyce et al. (2009) in that such media coverage invoked fundamental political campaigns, Chan et al. (2010) state that the media's

preoccupation with hospital cleanliness caused finger-pointing at political leaders with allegations of corruption and concealment, thus evoking further political conflict. However, this ultimately led to new cleanliness guidelines and attracted more resources to deal with the problems.

Although no media coverage analysis has been conducted in relation to *C.difficile*, this understanding of how the media framed MRSA provided an insight into the information that the public are exposed to by newspapers and therefore can help us to better understand to some degree how and why people make sense of such representation.

Reception

It is argued that media coverage can lead to the overestimation of small probability events by the public and irrational risk perceptions, which subsequently causes misplaced choices and distorted prioritisation (Lyons 2000, Bomlitz and Brezis 2008, Besley and Nisbet 2011). Jackson (2000) also claims that the media abuse scientific information through misinterpretation, thus creating unwarranted upset and alarm for healthcare professionals, patients and relatives. As a result, the media can influence inappropriate behaviour. For these reasons, distrust towards media professionals is reported (Hall et al. 2003, Chan et al. 2010). However, many of these assumptions appear to be largely hypothetical and unsubstantiated rather than the result of robust empirical research (Collins et al. 2009).

Kitzinger (1999a) argues that such unsupported claims are actually often themselves indiscriminate and exaggerated.

Wählberg and Sjöberg (2000) argue that despite accusations of sensationalist reporting, journalists are not always biased towards the dramatic aspects of a risk story. Rather they may just simply fail to put it into context or perspective or do not provide an explanation of technical terminology used. As a result, the reader is often left to interpret the risk which is based on incomplete information. Boholm (2009) further pointed out that the transfer of media content to an audience is not simple, but rather the result of a complicated two way interaction. Audience reception studies have reported a number of factors to be particularly important in how media messages are received and interpreted, such as direct and indirect experience, the use of logic and identification of contradictions and cultural affiliations, political sympathies and value systems of group members (Philo 1990, Philo and Henderson 1999). These studies conclude that audiences do not typically make their own meanings from media text, rather via these complex processes they choose to accept or reject them (Philo 1999).

A study by Henderson (1999) found that there was considerable diversity in the way women related to media reporting of breast cancer. For example, some women believed it was necessary to ignore some media messages about breast cancer, even educational messages during breast cancer awareness month as it was perceived to be distressing. Different factors were

reported to influence such perceptions. For breast cancer survivors, they felt they were being bombarded with media information at a time when they were trying to recover and get back to normal life. Others who had no experience of breast cancer stated it made them frightened of what could happen so they tried to avoid reading media stories about it altogether. Such perceptions and responses are also reported by others (Kitzinger and Davidson 2001). In contrast, women who were less fearful about breast cancer appeared to be more responsive to breast cancer information in the media.

While it is evident that the media help shape public risk perceptions and responses, it is important to acknowledge that the media are also influenced by their consumers and other key factors. Gaining an understanding about how and why risk issues are produced by the media will help shape more effective risk management and communication strategies. This literature around audience reception aids our understanding of how individuals make sense of media representation of specific health-related risk factors and also helps to identify ways in which the media operates and why some media messages 'succeed' when others fail (Kitzinger 1993, Miller and Reilly 1994, Kitzinger 1999b, Reilly 1999). Moreover, it provides an insight in to how media text can be interpreted and used by individuals (Philo 1999). What was notable however from these studies is that they solely focus on how the *public* make sense of and respond to media representation. Even though it is reported that the media are often used as scapegoats by expert about risk issues (Sjöberg et al. 2004), no study could be located exploring how experts

make sense of health-related risks in the media. Given that healthcare professionals presumably also read newspapers, it seems strange that this remains unexplored.

Production

A study undertaken by Breakwell (2001) aimed to establish what factors affected the way in which journalists and editors reported stories about hazards and risks. Within this study, they reported that many journalists and editors actually had difficulty defining risk in terms of what a 'risk story' was because they considered life in general as being risk-laden. However, they stated that 'scare stories' were of particular interest as they were seen to be the main selling point of a newspaper as they are good for audience building. These included stories that were a threat to a large number of individuals, focusing on the blameless and the defenceless, especially in connection with women and children. Notably, they felt that women were also good targets with regards to health issues as they tend to be more health conscious than men and would therefore generate stronger reactions. Journalists also stated that scare stories were likely to be most effective if they were personalised and particularly if 'victims' were identified, especially if they were well known celebrities. This is congruent with the explanation by Kitlinger (1999a) whereby the absence of existing victims may make a story less newsworthy and prospective or hypothetical victims do not seem to be enough to guarantee coverage. However, journalists refuted accusations of sensationalist coverage of such scare stories in favour of 'infotainment', this being the act of

providing information in a way that is entertaining and therefore more newsworthy. They did however recognise that this could entail some exaggeration.

Even with less controversial health-related risk topics, a journalists' main goal is to seek out a newsworthiness aspect from it. For example, through interviews with 40 journalists and their sources (cancer research and support organisations), Kitzinger and Philo (1999) examined the processes that influenced journalists coverage of breast cancer. While journalists generally agreed that breast cancer was an easy story to report about because it always attracts interest, they highlighted the importance of identifying a specific 'hook' in order to make it newsworthy. For example, one journalist stated that the epidemiology of the disease would not be appealing. Rather, hooks like celebrity deaths, scandals with regards to healthcare related mistakes and campaign initiatives would be much more favourable because they generate reader interest.

These views also fit with a study by Balasegaram et al. (2008). They interviewed nine health journalists to gain an insight into factors that influenced reporting about neglected infectious diseases. Most journalists stated that for them, a newsworthy story would need to feature 'real people' rather than simply reporting information provided to them by 'experts in their ivory towers'. Key to this was the inclusion of the 'yuck factor' about the disease or outbreaks which could be played up to 'grab the public imagination' rather than just

providing facts about the life cycle of disease. For example, they stated that poor people dying from an illness was not considered news whereas more interesting disease-related deaths such as HIV/AIDs sells stories. However, such views have been contested by other journalists who argued that their main aims were to educate and inform, to dispel myths and to get it right (Bertrand and Huges 2005). Indeed, others also stated that they spent a great deal of their time trying to convince editors *not* to run some stories because they had been sensationalised in other competing newspapers (Williams and Clifford 2009).

Even if a risk issue is reported, there are however, fundamental factors that impact on the depth of coverage it will receive. Kitzinger and Reilly (1997) found that with complex and specialist topic issues, journalistic training and news gathering can operate against in-depth coverage. For example, some journalists stated that they would shy away from topics about which they have little knowledge or understanding as this disadvantages them. Additionally, very tight deadlines prevented them from having the time to research the topic in any depth. As a result, a journalist may either wilfully or inadvertently omit important information which could potentially distort the interpretation of a story. Similarly, Voss (2002) found many journalists stated that they often had difficulty understanding key health issues and interpreting health statistics, and that they were not confident about their ability to report on health issues. However, due to the pressure to still report on these stories, they believed that many journalists frequently fail to provide accurate context for health stories.

One of the most influential aspects of producing risk stories in the newspapers is the presence and quality of sources. Balasegaram et al. (2008) found that official sources are often reluctant to communicate, and even if they do provide information, it is often limited. In contrast, pressure groups are usually keen to speak to the media, but they are not the most favourable people for journalists to use as sources because they usually come with their own particular agenda that more often than not is different to that of the journalist (Williams and Clifford 2009).

When official sources are used, according to Williams and Clifford (2009, p.53), these are frequently gained through press releases and are often simply a “*cut and paste job*”. Journalists also stated that even with information gained through such sources, there is still often not enough time to verify facts, therefore they have to rely more on trust of that source than they would like. An exemplar given by one journalist was that universities are employing more press officers who are getting more and more skilful at making rubbish research look good and with pressure from editors and time restraints it makes their ‘life fifty times harder’. They stated that although through this method a story may be half written for them, there is no journalistic substance to it. According to Williams and Clifford (2009), such constraints have led to a number of detrimental effects on news reporting. For example, many journalists argue they now have less time to research and fact-check stories than they previously had done, with some admitting that they do not even have the time to adequately check over the stories to which they put their names.

Additionally, they reported that due to the high-speed nature of daily print journalism, journalists and editors may deliberately turn a blind eye to errors.

By exploring how and why the media report health-related risk issues in the way that they do enables a deeper understanding of their role. Holtz (2010) also adds that what people continually fail to recognise is the difference between the role of health risk educators and the role of journalists. He stated that while many news stories contain useful health information, the role of a journalist is simply to tell people what is going on in the world or in other words, to report the news. As such, messiness, confusion and conflict are often inherent within such stories. Furthermore, Larsson et al. (2001) point out that a journalist's role is not to promote science or effective and efficient healthcare. In contrast, the role of health risk educators is to provide clear consistent and persuasive messages intended to influence specific attitudes and behaviours. Such differences in roles therefore leads to continual tension and frustration between experts and journalists, and often results in contradictory risk communication which can enhance confusion, uncertainty, and fear (Ransohoff and Ransohoff 2001).

Summing up

Acknowledging the complexity of media influence on risk perceptions and responses, it is evident that to understand the whole picture of the role of the media in terms of health-related risk reporting, representation, reception and production exploration is required. By doing this, unsupported assumptions of

stereotyping and misrepresentation and engagement in debates about the accuracy and quality of media products as well as broader social issues and political struggles can be challenged. Moreover, through gaining such an in-depth understanding of the role of the media, the coverage of risk issues and potential responses to coverage can be influenced and pre-empted and thus incorporated into risk management and communication strategies.

Part five: Concluding remarks from the literature reviews

These scoping and structured literature reviews have explored the literature around risk perceptions and responses from a broad perspective, and risk perceptions and responses of the public and healthcare professionals within the context of *C.difficile* and other healthcare associated infections. The review work also explored the literature around the role of the media in risk reporting. Taking into account the theoretical and empirical literature examined for these literature reviews, the following conclusions are drawn:

- The complexity of how and why risk perceptions are formed, shaped and responded to cannot be explained by a single risk perception theory. Current theories however can be drawn on in order to help conceptualise factors that influence risk perceptions and responses and can be helpful in guiding empirical studies.
- Risk perceptions and how people respond to risk are context dependent. In other words, individuals can only form perceptions about a risk and respond to a risk based on the situations in which the risk is experienced.
- There is a wide range of broad empirical research which provides an insight into some factors that are important in influencing risk perceptions and responses. These include uncertainty, heuristics, familiarity and controllability. This body of literature can help form a broad understanding

when seeking to explore risk perceptions and responses in specific contexts.

- There are variations in risk perceptions and responses between the public and experts. The literature asserts that experts think about risks in terms of measurable probabilities based on scientific evidence and are therefore thought to be rational. Public risk perceptions and response on the other hand, are formed by subjective interpretations and judgments and often on emotion. As a result they are often dismissed as irrational. This however continues to be widely debated as some argue expert and public risk perceptions are more complex than is often suggested. There is very little knowledge of these variations in the context of *C.difficile*
- There have been no robust studies to date that gain an in-depth understanding of risk perceptions and responses in the context of *C.difficile*. What there is provides us with a some understanding of *what* individuals' risk perceptions are but adds little to our understanding of *how* and *why* individuals perceive in the way that they do. Additionally, some of these studies lack methodological quality.
- The media is one of the most influential determinants in shaping risk perceptions and responses. However, due to the complex and multi-faceted way in which risk perceptions are formed, shaped and responded to, it is not yet possible to determine how influential the media are. Yet, the

media are frequently blamed for creating further public uncertainty, panic and fear through accusations of inaccurate, sensationalist and dramatic reporting.

- To fully understand the role of the media in health-related risk reporting and gain an insight into how and why the media can impact on risk perceptions and responses, media representation, audience reception and media production need to be examined.
- There is no empirical research that examines media representation of *C.difficile*. There are a few studies that examine media representation of MRSA which provide a little insight into risk reporting of healthcare associated infections.
- There is no empirical research that examines audience reception of media coverage of *C.difficile*. Some understanding of how and why individuals make sense of media coverage was gained from a small body of literature in relation to wider health-related risks.
- There is a small body of empirical research that examines media production of health-related risk stories. These studies provide a basis for further empirical exploration around the objectives of media professionals in health-related risk reporting.

- Individual's risk perceptions can have a significant impact on how people respond to risk issues. Understanding risk perceptions is therefore fundamental in helping inform risk management and communication strategies

These literature reviews demonstrate that risk perceptions and responses are context specific. Within the context of *C.difficile*, there is a significant lack of understanding about how and why individuals perceive and respond to risk factors. The literature asserts that the media plays an important role of shaping risk perceptions and responses, but no empirical evidence is available to support this. Cormick (2009) argues that risk perception research must go further than simplistic polling and identifying what people think. Rather, using qualitative research, further understanding is required around what factors impact on risk perceptions and responses. In doing so a better understanding of individuals' needs and desires will be achieved which can be matched with future risk management and communication strategies.

Research aims and questions

Taking into consideration the issues identified in the wider literature around risk perceptions and responses and addressing the gaps identified, this study aims to explore public and HCPs' risk perceptions and responses in the context of *C.difficile* and examine the role of the media in health-related risk reporting. In doing so, the following research questions are posed:

1. How was information about *Clostridium difficile* and associated individuals framed in the newspapers during an outbreak?
2. How and why do the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?
3. Are there similarities and/or differences in the way the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?
4. What factors influence the way in which health-related risks are produced in newspapers?

Chapter Three: Methodology and research approach

Introduction

This research was a qualitative study using interpretive description methodology and is philosophically underpinned by weak social constructionism. Data were generated through a media coverage analysis of a *C.difficile* outbreak, focus groups with the public and healthcare professionals and semi-structured in-depth telephone interviews with media professionals. This chapter critically discusses the literature pertaining to the methodology, philosophical approach and the research design chosen for this study, and provides a rationale for the choices made.

Qualitative research

Within nursing, qualitative research is concerned with the exploration of views, beliefs, feelings and experiences of individuals in order to apply findings to healthcare practice, inform policy and drive forward research (Lipscomb 2012, Cleary et al. 2014b). Given its significant contribution to theoretical knowledge and practical use, qualitative research has grown in popularity over recent years, particularly in healthcare and nursing (Miller 2010). One of the fundamental strengths of qualitative research is eliciting in-depth accounts of human perceptions, real-life meaning and experiences so that in-depth explanations and interpretations about a phenomenon can be developed (Joubish et al. 2011, Barbour 2014). Thus, it is concerned with an individual's

perceived reality and the exploration of the 'how' and 'why' questions within specific contexts. Furthermore, qualitative research can allow for the exploration of narrative accounts that occur within the original context to be achievable (Castro et al. 2010). This enables the researcher to inductively derive concepts and ideas from participants, rather than deductively imposing a specific concept onto them (Lipworth et al. 2010).

With regards to risk perceptions and responses, the literature review demonstrated that individual's realities are not dichotomous and fixed. Rather, people draw upon a diverse and, at times, ambiguous range of socially and contextually mediated subjective interpretations in order to make sense of and respond to risk. This highlights that understanding subjective expressions of risk is incongruent with approaches that emphasise objective measurement. Furthermore, the literature review highlighted that not enough is known about the contextual and social processes in which risk perceptions and responses towards *C.difficile* are shaped to allow for exploration using an objective approach. Rather such exploration is better suited to qualitative inquiry. By choosing to adopt a qualitative approach, it enabled close engagement with participants to allow meaning from participants to emerge and elicit in-depth insight into the social processes in which meanings were created and recreated (Barbour 2014).

Within qualitative research, there are a range of methodologies that can be used, all of which provide an overall strategy for formulating, articulating,

analysing and evaluating methods. Of these, no one is better or worse than the other as each has their own set of strengths and limitations. Indeed, many 'borrow' certain elements from each other (Silverman 2005). However, different methodological approaches involve different philosophical assumptions in order to clarify how the knower will go about finding out the to-be-known and undertaking the research (Denzin and Lincoln 2003). Rather than research being methodologically led, the choice of methodology should be informed by the researchers philosophical (epistemological and ontological) stance and the social phenomenon that is under investigation (Sim and Wright 2000, Jackson 2013).

Ontology refers to the perceived nature of reality and what there is that can be known about it. Tuli (2011) points out that the interpretive researcher's ontological position does not accept that the idea of a reality exists irrespective of other people and social influences. Denzin et al. (2006) elaborate further in describing the world as constructed, interpreted and experienced by individuals who make sense of their internal reality as they interact with the world around them.

Epistemology is the 'theory of knowledge' (Carter and Little 2007). It is concerned with the meaning that is ascribed to knowledge and how it is created, and therefore guides the methodological decisions. Interpretive researchers' view themselves as empathetic and remain at the core of the research so that they can fully understand their participants' perspectives and

focus on sense-making (Darlaston-Jones 2007). In other words, as Streubert and Carpenter (2011) explain, the researcher allows themselves to get inside the world of their participants in an attempt to really understand how they construct their reality within their social and cultural context.

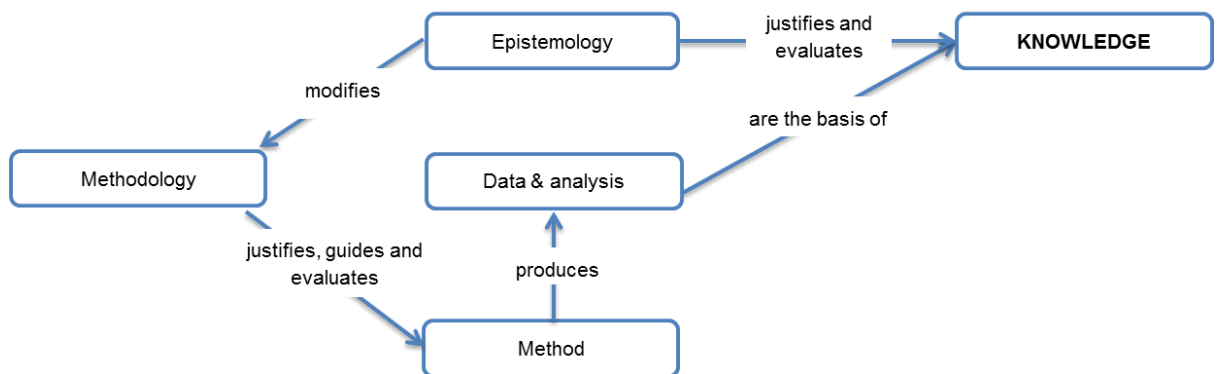
According to Barbour (2014), however, novice qualitative researchers can often be assailed with a confusing variety of contradictory philosophical claims. She and Ormston et al. (2003) endorse the advice offered by Hammersley (2004, p.557) in that while it is important to have an understanding of different philosophical perspectives, novice researchers are encouraged to become “*neither ostriches or fighting cocks*”. To assist with the navigation of this “*difficult terrain*”, Barbour (2014, p.44) advocates moving beyond just focusing on distinct differences between approaches. She states that researchers should therefore, cultivate open-mindedness about them to prevent being forced into a philosophical or methodological straitjacket. Ultimately, this will acknowledge that these assumptions are simply part of the researchers overall toolkit rather than being viewed as competing and contradictory approaches (Ormston et al. 2003).

Nevertheless, understanding philosophical assumptions in qualitative research and how they manifest themselves within the methodology and research design is important, and it also enables others to better comprehend, question and apply the research that they study (Krauss 2005, Scotland 2012). As there are strengths and limitations in all philosophical assumptions noted

in the literature, no approach can be considered right or wrong (Wong et al. 2011, Tuli 2011). Rather the philosophical position adopted by researchers is chosen on the basis of what they want to know (Sobh and Perry 2006).

Acknowledging these challenges in understanding the facets in qualitative research and their relationship with each other, Carter and Little (2007) provided a comprehensive framework to illustrate this (Figure 4)

Figure 4: Qualitative research framework



(Carter and Little 2007)

The philosophical positioning in relation to this study is that of weak social constructionism. This was selected on the basis that people construct understandings about risks associated with *C.difficile* from the social world around them and that there cannot be an established clear or singular view of the world as it exists from multiple perspectives or 'realities'. Within the risk perceptions and responses arena, this was supported by the literature review. In this sense it promotes the importance of how individual perceptions and

behaviour are socially and contextually constructed and therefore, should not be viewed as being fixed nor certain (Burr 2003, Seale 2012, Barbour 2014).

Social constructionism

Social constructionism is recognised as an influential philosophical approach to qualitative research and has made significant contributions to the understanding of the social dimensions of health and illness over recent years (Burr 2003, Corad and Barker 2010, Silverman 2011). The essence of social constructionism is that knowledge and truth is created socially, not discovered by the mind (Schwandt 2003). Thus, it is the creation of an individual's 'reality' which occurs through social relationships and interaction (Nightingale and Cromby 2002, Seale 2012).

A social constructionist's position can be explained by four key assumptions (Gergen 2001, Burr 2003). Firstly, a critical stance is taken towards taken-for-granted knowledge. In other words, it invites us to adopt a critical view in order to challenge the assumption that knowledge is based upon an objective, unbiased observation of the world. Secondly, the ways in which we understand the world are historically and culturally specific. By this, Burr (2003) explains that perceptions and knowledge are dependent on where and when in the world we live. As a result they are not static or inevitable, but are historically and culturally situated and this will change through time and space (Cohen et al. 2004). The third assumption is that knowledge is sustained by

social processes in that people create their knowledge through the daily interaction between people and social life. Social constructionists therefore argue that it is impossible for us to create our knowledge independently of other people and our social world. Burr's fourth and final tenet is that knowledge and social action go together. This means that the way people respond both physically and emotionally in life are influenced by the knowledge that is created through interaction with the world. As a result when new or different knowledge is created, social action changes accordingly (Edley 2001) .

One of the main challenges social constructionists are faced with is that they are often subsumed under the notion of social constructivism. Although a common denominator between the two is that their interest focuses on meaning-making, there is a fundamental distinction (Stamm 2001, Engler 2004, Young and Collin 2004). In contrast to social constructionism whereby reality is constructed *through* social interaction, social constructivism rests on the ontological position that reality occurs from the *outcome* of social interaction (Kwan and Tsang 2001, Nightingale and Cromby 2002). As such, social constructivists employ an ontological principle of relativism (Stamm 2001, Doucet et al. 2010). This means that no truth or realities can be established because of the belief that the reality can change frequently depending on the social interactions individuals have (Lincoln and Guba 2000). This distinction between the two philosophical approaches has

important implications as research is driven by the assumptions on which these approaches are based.

Within social constructionism, two camps exist: *strong* social constructionism and *weak* social constructionism. Strong social constructionists adopt a more radical epistemology and regard *everything* as a social construction. They therefore do not recognise an objective reality and believe nothing exists beyond language. The implication of this is that there is no way of judging one person's account of reality with anyone else's (Burr 2003). Sayer (1997) pointed out that because there is absolutely no objectivity, participants' and researchers' interpretations and constructions are revisable at any time. Thus he argued that the revisions of a researcher's constructions and interpretations can take place without any revision of participants' constructions, which evades the question of the relationship of social constructions to the nature of their referents.

In contrast, *weak* social constructionists still embrace the concept that knowledge and reality is socially constructed and align themselves with Burrs' four key assumptions outlined earlier (Burr 2003). However, they recognise that social constructs are dependent upon underlying objective elements to reality. In this sense, weak social constructionists do not entirely reject the notion of an objective understanding of truth (Sayer 2000). Rather they make the important distinction between beliefs, knowledge and perceptions which are socially constructed and which have a real existence (Jacobs and Manzi

2000). This, as Jacobs and Manzi (2000) argue avoids endorsing an extremist idealist epistemology which claims the world is solely socially constructed and therefore rescues social constructionism from accusations of extreme relativism.

In terms of applying this to the context of this study, *C.difficile* is a risk. It is a viable healthcare associated infection and so it is considered 'real' and it exists independently of the mind. However, what, how and why people make sense of it can only emerge through their interaction with the world around them. Some may suggest that these perceptions of reality may be tenuous. However, this is not the ultimate point. The point is that *C.difficile* is real and individuals' perceptions and experiences of it have real consequences. Thus, their reality emerges through their social and cultural creation of it.

Methodology

Interpretive description

Interpretive description (ID) was used for this study. The process of deciding which approach to take was challenging and involved a considerable amount of time, reading, reflecting, writing and having frequent discussions with supervisors and other research experts. The main dominant qualitative methodologies initially considered were phenomenology, ethnography and grounded theory (Moriarty 2011). Although these are all robust and widely adopted methodologies, it was noted that they originated from sociology, anthropology and philosophy and were, therefore, designed for use in non-

nursing research. As a result, there seems to be a large body of nursing research that does not appear to 'fit' with these particular methodologies (Thorne 2008). For this reason, nurse researchers may choose to adopt a generic qualitative approach and therefore fail to subscribe to any particular methodological viewpoint (Caelli 2001, Merriam 2009). Adopting such a generic approach however, has been criticised for its simplicity and lack of rigor and is often dismissed as poor quality (Arminio and Hultgren 2002, Tobin and Begley 2004, Ryan et al. 2007).

In an attempt to avoid such criticisms, nurse researchers often find themselves attempting to *fit* their work into one of the aforementioned dominant qualitative methodologies, even if the research design is incongruent with their choice (Hunt 2009). Indeed, some also often end up subconsciously borrowing and combining certain elements from different methodologies. This is what Neergaard et al. (2009) refers to as 'posturing' and argues that due to the lack of methodological rigor, these studies run the risk of making little methodological or theoretical contribution. Baker et al. (1992) also warned against this, referring to it as 'methodology slurring'. Morse (1989, p.15) also pointed out that "*it violates the assumption of data collection techniques and methods of analysis of all the methods used. The product is not good science; the product is sloppy mishmash*". For example, Cutcliffe (2005) reported a wealth of studies which have professed to be based on grounded theory methodology. However, on examination of these studies, there were a diverse range of processes and methods used which had limited grounded theory

methodological similarity, and at times appeared to have only a passing resemblance to grounded theory methodology.

Taking into consideration risk perception theories, the philosophical approach used for this study, and the research questions, it became evident that the dominant qualitative methodologies did not align with this study. Additionally, due to the issues around rigor, adopting a generic qualitative approach or indeed not subscribing to any particular methodology was also not considered appropriate. Neergaard et al. (2009) argued that one way of preventing posturing from occurring is to adopt a qualitative description methodology. They state that qualitative description is widely used by nurse researchers because it enables preliminary insights into experiences and views of individuals, and can also yield a working hypothesis or extrapolate key categories for further research.

However, while the contribution of qualitative description methodology in nursing research is not being called into question, it was not considered appropriate for this study. Although researchers using this methodology stay close to their data, the concern was that they do not move far from it. In other words, they provide a comprehensive summary or description of the phenomenon, with little more than a basic interpretation of the data (Sandelowski 2002). Given that the theoretical and epistemological position of this study has a focus on meaning-making and that new insights were to be

presented through them, more interpretation of the data was needed than is usually required for qualitative description methodology.

Acknowledging the challenges around dominant methodologies often failing to align with nursing research, nursing scholars Thorne, Kirkham and O'Flynn developed ID (Thorne et al. 1997). Notably, Thorne (2008) is adamant that ID is not a 'cookbook', nor it is a prescriptive, circumscribed sequence of steps. Furthermore, she also states it is not an entirely novel or distinctive approach which proposes methodological options that would be unfamiliar to nurse researchers. Interpretive description offers a range of coherent strategies for sampling, data generation, data analysis and interpretation and reporting for qualitative research so that credible and meaningful insights can be drawn with a focus on generating clinical practice knowledge (Kolverd et al. 2012). These strategies will be discussed in further detail later in this chapter. As it also creates a sense-making structure for the eccentricities and variations that inevitably occur in nursing and healthcare, Thorne et al. (2004) asserts that the development of new knowledge can therefore be applied without sacrificing methodological integrity. It is not surprising that ID has become increasingly popular among nursing and healthcare researchers over recent years (Jurgensen et al. 2012, Rapoport et al. 2013, Jensen et al. 2013, Thorne et al. 2013, Macartney et al. 2014).

With regards to the relationship between ID and the researcher's philosophical positioning, ID posits the view that human experiences and views are socially

constructed and that reality involves multiple constructed realities that may well be contradictory. As a result, ID acknowledges that there is an inseparable relationship between the knower and the known and that the inquirer and the object of that inquiry interact closely with each other (Thorne 2008). Thus, ID connects closely with social constructionism because the role and responsibility of the researcher is to create meanings from what is being studied. In doing so, ID is concerned with making sense of something and attributing meaning to it so that it can be applied to practice. It is the applied nature of these interpretations that lies at the heart of ID. For example George (2010, p.1627) states:

“For practitioners, seeing or hearing something in our work is only a portion of what we actually do in practice. In order to take action, we need to understand and make sense of what we see to make decisions, ask more questions, make plans, create solutions – apply knowledge”.

The main focus of ID, therefore is to generate better understanding of complex healthcare-related issues which stay close to what is important to healthcare practitioners and organisations so that it can be applied to practice in order to have a direct influence on practice and policy (Thorne 2008, Kolvered et al. 2012).

In terms of its relationship with theory, ID does not set out to test theory or locate itself with a particular theory, nor does it begin with no theory at all.

Rather, as Oliver (2011) explains, researchers locate themselves loosely within a theoretical framework that surrounds their discipline. This allows them to have an initial conceptual understanding which can be used to help develop and progress through the research process. Such a positioning ensures that the findings and subsequent interpretation will contribute to a larger theoretical assumption within the discipline (Thorne 2008). The risk perception theories discussed in Chapter Two enabled this initial conceptual understanding to be gained, in addition to identifying gaps. Consequently, these gaps were able to be considered during data analysis and subsequent interpretation and explanations made as to how the findings of this study could further add to current risk perception understanding.

Data generation

When selecting data sources for qualitative research, it is crucial that they are appropriate for the philosophical assumptions made and the methodological approach, and that they will provide answers to the research questions (Al-Busaidi 2008). The data sources used for ID should, therefore, be grounded in an interpretive orientation so that the constructed and contextual nature of health and illness experiences and views are recognised (Stajduhar et al. 2010). Yet, at the same time, the methods chosen need to be appropriate to generate shared and socially constructed realities (Thorne 2008). To achieve this, Thorne (2008) encourages the use of multiple data sources so that researchers have the opportunity to expand the scope of their inquiry and broaden the reach of their sample.

When using multiple data sources, however, care must be taken as to how and why they are used. Multiple data sources are often termed as methodological triangulation, which assumes that there is a 'fixed point' or 'object' that can be triangulated (Tobin and Begley 2004). Additionally, triangulation often takes the form of concurrent data collection in a linear process (Casey and Murphy 2009). For example, data collected in one phase will often contribute to the data collected in the next phase, thus enabling the validation of one data set with another (Seale 2012). As a result, the outcome of triangulation, as explained by Tracy (2010) assumes a single reality.

In order to gain a more holistic understanding of a phenomenon, rather than adopting the concept of triangulation, Richardson (2000) advocates using multiple data sources to achieve crystallization. The notion of crystallization is that the crystal is seen as a central imagery that combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multi dimensions and angles (Ellingson 2009, Denzin 2010, Watkins 2011). In other words, researchers resist the temptation to pull together a finished, polished, complete picture from the composite pieces of the data and attempt to *"tie up empirical loose ends"* (Gabb 2009, p.37). Richardson (2000) points out that crystallization demonstrates how many threads of data need to be integrated through each data set in order to retain the methodological and conceptual 'messiness' which characterises socially constructed meanings.

The concept of crystallization aligns within ID and weak social constructionism because it accepts multi representations of reality and allows the researcher to encounter and make sense of the data through more than one way of knowing. Multiple ways of knowing, according to Ellingson (2009), is analogous to viewing a phenomenon through a crystal. Taking into consideration the research questions and ensuring a flexible, yet structured, approach to generating and analysing data, multiple data sources were used in the form of print media, focus groups and semi-structured, in-depth interviews.

Print media

Newspapers are the largest media conduit for information and are a leading source of health information for the general public and healthcare professionals (Bomlitz and Brezis 2008). Furthermore, they are an important part of the process of how people construct and modify risk perceptions (Kitzinger 2008). Through the way in which news is represented, media professionals suggest ways to make sense of the world and have the potential to mould or structure people's perceptions in ways that are socially and politically consequential (Park and Sohn 2013). Furthermore, they can provide a voice for individuals to express their experiences of health, wellbeing and illness (Schwitzer et al. 2005). It is, therefore, unsurprising that media representation can have a significant influence on health behaviour, healthcare utilisation, healthcare practices and health policy (Larsson et al. 2001, Van Eperen et al. 2010). As a result, analysing how health-related risks

are represented in the print media is becoming increasingly popular in qualitative health-related research (Wilson et al. 2004, Clarke and Everest 2006, Boyce et al. 2009, Metcalfe et al. 2010, Bell and Seale 2011).

A media coverage analysis of a *C.difficile* outbreak was thought to be an important part of understanding the role of the media in health-related risk reporting. Additionally, it was believed to be important for helping understanding how media coverage may impact on how people use media coverage to make sense of issues regarding *C.difficile*. The media and risk research model developed by the Glasgow Media Group as discussed in Chapter Two in terms of representation, reception, and production was instrumental in informing the decision to use print media as a source of data for this study. For example, the media coverage analysis would provide the representation element, the public and healthcare professionals' focus groups would generate insight into the reception of media coverage and the interviews with media professionals would generate insight into the production of media coverage. This would enable a fuller understanding of the role of the media in relation to risk perceptions and responses.

Focus groups

Focus groups are a highly effective tool, used as a standalone method or in conjunction with other quantitative or qualitative methods, for researchers seeking to engage with participants (Freeman 2006, Jayasekara 2012). They allow for in depth analysis of conversations about perceptions and

experiences within a social and cultural context so that comparisons can be made both within and between groups (Flick et al. 2004, Barbour 2007). A crucial element of a focus group discussion is the interaction processes of the group. This allows the researcher to explore issues such as peer sharing, affirmation and reciprocal support, and the articulation of group norms and experiences and differences between individuals and groups (Carter et al. 2008, Nicholas et al. 2010). Such interactions, which go untouched in survey methods, can then be closely examined and analysed and become a valuable part of data interpretation (Lehoux et al. 2006, Hemsley et al. 2008). This enables observation of not only how people theorise their own perspective, but how they do so in relation to other people's points of view and how they locate their perspective in different contexts, thus drawing upon how perspectives are socially constructed (Baernholdt et al. 2010, Gullifer and Tyson 2010, Diaz et al. 2010).

Focus groups however, are not without challenges. For example, group discussions inherently create strength in numbers which may intimidate some participants and impose pressure or relational challenges on others within the group (Barbour 2007). Researchers, therefore, need to possess good moderation skills such as excellent listening, observation and speaking skills in order to foster a safe, open and honest dialogue so that meaningful discussions can be facilitated (Wong 2008, Merryweather 2010). Additionally, due to the amount of data that can be generated even by one single focus

group, transcribing and analysing can be complex and labour intensive (Nestel et al. 2010).

The decision to use focus groups to generate data from the public and healthcare professionals for this study, supported the views of Gaskell et al., (2004) in that it enabled in-depth exploration of current positioning that underpins opinions and judgments with regards to risk perceptions and responses. Moreover, as focus groups are shaped by multiple social contexts (Hollander 2004), they were considered the best method in which to illuminate social constructs of risk perceptions and responses. Thus, the goal was to observe the transformations that occurred as perceptions and experiences circulated about different issues being discussed and to discover how individuals made meaning of risk messages and what functions these meanings had for them (Joffe 2003).

Semi-structured, in-depth telephone interviews

The purpose of the qualitative in-depth interview is to understand and explore the world from an individual perspective, to unfold the meaning of their experiences and to uncover their lived world in relation to a specific phenomenon (Turner 2010). However, as pointed out by Gill et al. (2008) they differ from focus groups because they are concerned with an individual's perspective rather than a group of people. As a result, the researcher can obtain significant, more in-depth, detailed information specific to one person, which is unlikely to be achieved in a focus group (McNair et al. 2008).

In-depth semi-structured interviews are usually conducted around a set of predetermined open-ended questions, while still allowing for other questions or probes emerging from the dialogue between the interviewer and interviewee (DiCicco-Bloom and Crabtree 2006, Galvin et al. 2011). This allows the researcher to have some degree of flexibility with the interview schedule (Mizock et al. 2011). For example, while the overarching topic will be similar for each participant, the direction of the interview questions may differ depending on the responses and interaction between the participant and researcher. Notably, this is the main factor that differentiates semi-structured interviews from structured interviews as structured interviews follow the same questions for each participant in a predetermined order to allow for exact replication with all participants (Stuckey 2013).

Owing to the ever increasing geographical diversity of research, the broader social change and technological advances, semi-structured interviews conducted via the telephone are becoming an increasingly popular alternative to face-to-face interviews (Irvine 2010, Fischer et al. 2011, Irvine et al. 2012). Advantages of telephone interviews include researching sensitive topics (Schmied et al. 2011), accessing hard-to-reach people (Jones et al. 2010), enhancing interviewer safety (Novick 2008), and can be undertaken with relatively low cost and resource implications (Holt 2010).

However, one of the challenges of telephone interviews is the absence of some contextual non-verbal cues, such as facial expressions and gestures,

which are an important part of the analytical process within qualitative research (Sturges and Hanrahan 2004, Kvale and Brinkman 2009). That said, Irvine et al. (2012) argue that while this may be construed as a disadvantage, researchers using telephone interviews tend to offer more nuanced reflections on how the lack of visual cues affects the interaction in practice compared to those who conduct face-to-face interviews. For example, they assert that if the researcher is skilful, he or she should be able to pick up on other effects such as monitoring the responses and emotions and the levels of interest and emotion by the interviewee, which can then be used as a source of data.

For this study, telephone interviews were conducted with media professionals. Interviews were chosen in favour of focus groups because in-depth exploration of participants' perspectives within the context of their own professional role and responsibilities was required to answer the research question. If focus groups had been conducted, drawing out the nuances from each participant would have been extremely challenging, therefore valuable data would likely have been lost. The interviews were also conducted by telephone rather than face-to-face because as media professionals' work is often based around last minute stories and tight deadlines, interviews could have been required to be re-scheduled at relatively short notice. Re-scheduling a telephone interview would therefore have had minimal impact on time or cost.

Sampling and recruiting

A common limitation around sampling identified by many qualitative researchers is that samples are not representative, therefore their findings are not generalisable. Researchers using ID have noted the same limitation (Wilkins and Woodgate 2011, Liu et al. 2012, Galdas et al. 2012, Dooks et al. 2012). However, as pointed out by Thorne (2008), the main goal when considering the sampling strategy in ID research is not to produce a representative sample so that statistical generalisations can be made as it can be with quantitative research. Rather it is to select a sample that will reflect diversity, provide as much potential for comparison as possible and ultimately generate appropriate data to answer the research questions (Barbour 2014). Furthermore, Polit and Beck (2010) assert that despite not always being realised by qualitative researchers, analytical generalisation can be made. This concept refers to making generalisings from broader constructs or theory that have been developed from the research, provided a transparent and rigorous approach to data analysis has been undertaken.

Gobo (2004) asserts that some researchers believe qualitative research does not require a formal sampling strategy, rather they hold the belief that sampling should be undertaken opportunistically. However, although a more flexible approach is usually adopted in comparison to quantitative research, Bryne (2001) warns that sampling in qualitative research requires careful consideration in order to prevent poor quality research. Thorne (2008, p.89) explain that in ID, there is no one best sampling strategy over another. She

argues that whatever sample is selected it should “*reflect a certain kind of perspective built from an auditable set of angles of vision whose nature and boundaries we can acknowledge and address*”. Sampling must therefore be undertaken on the basis of a transparent sampling logic and that findings must be reported in keeping with what researcher understands their sample to represent.

The most common sampling strategy used within ID, as with much qualitative research is purposive sampling where participants are deliberately selected depending on specific characteristics important to the inquiry, such as geographical location, age and gender (Gullifer and Tyson 2010). Similar to most qualitative research, ID does not favour a specific sample size, although when seeking an in-depth understanding of a phenomenon, samples sizes are usually fairly small (Barbour 2014). According to Thorne (2008), the best way to justify the sample size chosen is to generate a rationale that is consistent with the research question.

Once the sampling strategy has been established, some argue that participant recruitment for qualitative research should continue until data saturation occurs i.e. when no further patterns emerge from the data (Gaskell 2000). However, according to others, researchers should be cautious using this term especially in relation to their epistemological position (O'Reilly and Parker 2012). For example, social constructionists believe in multiple realities in that each individual has their own perceptions and views, data saturation can never

truly be accomplished. Rather, it is beneficial to continue to sample until the research aims have been achieved and the research questions have been addressed (Cleary et al. 2014a). In terms of participant numbers in focus groups, the suggested optimum number varies between researchers (Carlsen and Glenton 2011). Freeman (2006) suggests that typically a focus group will consist of between six and twelve participants, which is substantial enough to gain a variety of perspectives and small enough not to become disorderly or fragmented.

For this study, purposive sampling was the initial sampling strategy adopted for focus groups, interviews and media coverage analysis. However, due to recruitment challenges with focus groups and interviews, purposive sampling was extended to include snowball and convenience sampling. The actual sampling processes taken for this study will be explained in detail in Chapter Four.

Data analysis

Qualitative data analysis is not a linear process. Described by Suter (2012, p.348), it is *“iterative, recursive and holographic with swirls and eddies”*. Often as a result of this, qualitative research questions are frequently refined and sometimes even reformulated as the study progresses (Hancock 2002). The process of data analysis is also rigorous, whereby raw data is reduced into a form of explanation, understanding or interpretation in order to answer the research questions (Thomas 2003). However, as qualitative research can

accumulate vast amounts of data, often from varying and diverse samples and by using different methods, analysis can be complex and labour intensive (Li and Seale 2007). As a result, many researchers simply aim for the identification of themes as a goal and an end point (Neergaard et al. 2009). Bazeley (2009) argues that data analysis needs to go beyond this in terms of contextualising and making connections between those themes so that a coherent argument supported by data is developed. Consequently, it requires a mix of creativity and systematic searching to condense, transform, interpret and represent the data in a rigorous and trustworthy manner (Seale 2001, Holloway 2011). For this reason, it is important that a clear data analysis plan with a robust analytic structure is developed (Miles et al. 2014).

A theory-driven approach to data analysis, i.e. using theory to inform data analysis, tends to be more structured, whereas data-driven approaches, i.e. allowing the analysis to emerge from the data without being influenced by theory is more flexible and open to the discovery of new themes and ideas that are grounded in the data (Fereday and Muir-Cochrane 2006, MacFarlane and O'Reilly-de Brún 2011).

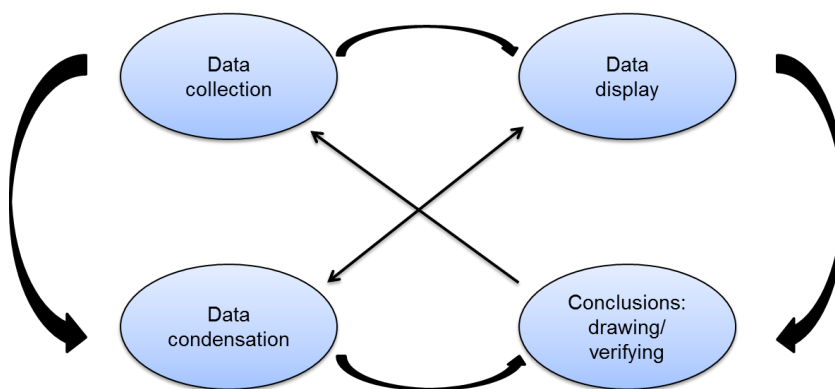
Within ID, Thorne (2008), advocates the use of theory-driven and data-driven approaches. Having an insight into related theory provides a scaffold in which to guide the research process. This then enables the researcher to navigate within and beyond the initial theory to allow a deep engagement with the processes of inductive reasoning. This includes testing and challenging

preliminary interpretations and conceptualising an ordered and coherent final product. In other words, the analytical process moves beyond the theory that provided the scaffold for the study and initial descriptive claims, towards abstracted interpretations that will illuminate the phenomenon under investigation in a meaningful manner (Thorne et al. 2004). To achieve this, Bazeley (2009) states that researchers need to ask more questions about their themes and patterns and record meaningful associations. In doing so, interpretation will subsequently attach meaning and significance to the themes and patterns identified (Taylor-Powell and Renner 2003). Thorne (2008, p.156) also explains that this will prevent “*premature closure*” whereby researchers may fail to develop meaningful findings because they stop at the first major experiential insight assuming that is all there is to find.

Miles et al. (2014) offer a range of widely used, rigorous and comprehensive qualitative data analysis approaches to help achieve the level of interpretation required in ID. These approaches are not a set of prescriptive step-by-step processes which need to be adhered to rigidly. Rather they can be selected and used on the analytical requirements of the study. Importantly, they enable the data analysis to be transparent throughout, allowing the reader to follow the analytical process and understand how interpretations were derived from it, thus enhancing rigor and trustworthiness (Rolfe 2006). Given that ID aims to make sense of meanings and interpret these meanings in the context of the study, using a data analysis approach developed by Miles et al. (2014) was thought to be the most suitable to use for the focus group and interview data

analysis. These approaches are embedded with four major overarching stages (figure 5). Each data analysis approach used will be described in detail in Chapter Four.

Figure 5: Components of data analysis



(Miles et al. 2014)

For the media coverage analysis, Framework was used to analyse the data thematically (Ritchie and Spencer 1994). Thematic analysis is the most commonly used approach for analysing media coverage and is the approach adopted by the Glasgow Media Group as it has proved to be effective for examining how key theses of social ideologies are represented in the media (Philo 1999). Framework is a widely used and effective tool with clear series of steps which allow researchers to manage and thematically analyse qualitative data. These steps are: familiarisation of data (reading through the data a number of times); identifying a thematic framework (based on the research questions, aims and theoretical frameworks); indexing (systematically applying the thematic framework to the data in its textual form);

charting (draw categories codes and sub codes from the thematic framework which represents themes from the data) and mapping and interpretation (sifting through the data and charts to create core themes, analysing it, defining concepts, finding associations and providing explanations for the data). The value of using this tool for thematic analysis is that it provides a clear and transparent step-by-step robust analytical process. Additionally, the flexibility of the tool is conducive to the iterative nature of the analytical process in terms of being able to move back and forth as ideas and concepts begin to emerge and mature.

Throughout the whole data analysis process, Miles et al. (2014, p.253) highlights the importance of “*keeping yourself analytically honest*”. Given that qualitative researchers often work by insight and intuition it is easy to overweight facts that conform to a researchers thinking or ignore data that does not. From a weak social constructionist stance, it was important to be mindful that the aim of the study was not to seek out a single truth or reality or to decide who is right or wrong. Rather it was about recognising multiple realities and to draw upon these to present coherent interpretations and explanations.

Data presentation

When presenting the findings of the focus groups and interviews, in order to illustrate perceptions, views and experiences, verbatim quotations were used.

Verbatim quotes were also used for the media coverage analysis to illustrate specific representations. Verbatim quotes are reported to be beneficial in illustrating what was said, how it was said and in what context, and are valuable in providing evidence for researcher's interpretations (Anderson 2010). In other words, readers who are able to see some of the original data can make their own judgements about the appropriateness and accuracy of the analysis and interpretation. Additionally, as asserted by Corden and Sainsbury (2006), this is an effective way to demonstrate transparency. Notably, some quotations used for the focus group findings may appear in places longer than interview data. This was necessary to illustrate how participants made sense of issues as a group and therefore formed shared constructions.

However, Richards (2005) cautioned that qualitative data are often presented poorly through a collection of long quotations stitched together by partial summaries which claim to represent the data. She likens this to a patchwork quilt, whereby there is no common weave across the pieces stitched together and therefore it offers no analysis or interpretation. Verbatim quotations for data presentation for this study were selected carefully to prevent this from occurring and to support contextualised interpretations while ensuring participants' accounts were reported accurately.

Summary

Following an in-depth exploration of the philosophical, methodological and methods literature, an ID methodological approach using mixed qualitative methods, underpinned by weak social constructionism was the most appropriate and effective approach in order to address the aims of this research and answer the research questions.

The philosophical position of a researcher relates to the way in which they look at the world they live in. Adopting a weak social constructionism position for study acknowledges that there is a reality out there that is independent of perceptions about it. However, it accepts that people's views, opinions, perceptions and experiences are subjective and socially constructed. In other words, a person cannot form a perception about reality in isolation of the social world around them. Alongside this philosophical alignment, ID takes into account the constructed and contextual nature of individual perceptions and experience while also allowing for shared realities. Thus, it aligns with the view that there are multiple constructed realities which are subjective and context dependent.

This chapter has provided a critical discussion of the literature pertaining to the philosophical and methodological approaches and the methods used for this study. In doing so, a rationale for the choices made was presented. The following chapter will now describe the methods, approaches and processes that were taken to conduct this study.

Chapter Four: Methods and research process

Introduction

This chapter will focus on the practical and procedural aspects of the research methods and processes. These include an overview of the study design, study settings, population and sampling, access and recruitment, data generation, data analysis and ethical considerations. It will also outline challenges that arose throughout the course of the research and discuss how these were addressed.

Study design

This study used qualitative mixed methods to generate data from 2010 - 2011. Data were collected through media coverage of a *C.difficile* outbreak, focus groups with the general public (n = 8), focus groups with healthcare professionals (n = 7) and one-to-one semi-structured in-depth telephone interviews and one face-to-face interview with media professionals (n = 10). A total of 39 members of the public and 29 healthcare professionals took part in the focus groups. In total, 78 participants took part in the study. Focus group and interview data were analysed using Miles and Huberman's qualitative data analysis approaches (Miles et al. 2014), and the media coverage was analysed thematically using Framework (Ritchie and Spencer 1994). NVivo 9 then 10 was used to assist with the analytical process.

Study settings

The study sites for the public and healthcare professionals' focus groups were the West of Scotland and the East of Scotland. The West of Scotland was selected on the basis that it had experienced a highly publicised *C.difficile* outbreak in the past and the East of Scotland had not. This subsequently afforded the opportunity to generate data from a range of individuals who would likely have been exposed to varying experiences and information in relation to *C.difficile* and potentially maximising diversity of different perspectives (Barbour 2014). The media professionals worked in varying locations throughout the UK.

Study population and sampling

The populations for this study were members of the public, healthcare professionals and media professionals. Members of the public were those living in the West of Scotland or the East of Scotland and healthcare professionals were those working in the West of Scotland or the East of Scotland. The study population for media professionals were those who were currently working for either regional or national newspapers in the UK.

For all populations and the print media, consistent with ID and aligning with weak social constructionism, the initial sampling strategy adopted was purposive sampling (as explained in Chapter Three). An inclusion criterion of geographical location (West and East of Scotland) was implemented for members of the public and healthcare professionals. Purposive sampling for

these focus groups also aimed to select participants based on a range of demographic characteristics such as age, gender and social experience to maximise diversity among participants (Onwuegbuzie and Leech 2007). For media professionals the requirement was having experience in health-related risk reporting in UK newspapers. However, due to recruitment challenges, snowball and convenience sampling were adopted and all participants who expressed an interest in taking part in the study were recruited. For the media coverage analysis, purposive sampling identified newspapers that had reported about a specific *C.difficile* outbreak. Sampling was also informed by readership, highbrow/lowbrow spread and the broad political shades of opinion.

When deciding on sample sizes and recruitment, there was no pre-determined number of interviews, focus groups or participants prior to data collection. Rather, recruitment conformed with O'Reilly and Parker (2012) in that it was based on the appropriateness of the data. In other words, sampling and recruitment continued until it was accepted that the aim of the research had been achieved and it was thought that sufficient data had been obtained in order to address the research questions.

Access and recruitment

The public

It is well documented that recruiting participants to engage in research is challenging (Howatson-Jones 2007, Graffy et al. 2009), therefore clear

recruitment strategies need to be in place (Dyas et al. 2009). Recruiting members of the public for this study was particularly challenging which resulted in the recruitment strategy being revised and modified four times.

Strategy 1 involved creating a colourful, laminated poster which provided a brief overview of the study and what would be required of participants. A deadline date and a contact name, email address and telephone number was also provided for people to express their interest in participating in the study (Appendix 3). The poster was placed in various public places in each geographical location, such as charity shops, taxi ranks, coffee shops, gift shops, newsagents and hairdressers. This strategy resulted in one response from the West and none from the East. A participant information sheet (Appendix 4), screening questionnaire (Appendix 5) and a stamped addressed envelope were sent to the interested participant from the West for completion, but nothing was returned to the researcher.

Strategy 2 involved advertising through local newspapers. Editors of local newspapers were contacted to ask if they would publish an article. All editors agreed to do this free of charge and articles were published the following week. As a result, one person from the West and four people from the East responded to express an interest in taking part. These people were sent a participant information leaflet, a screening questionnaire and a stamped addressed envelope. All five were completed and returned.

Strategy 3 was word of mouth through friends and colleagues in addition to snowball sampling from participants who expressed an interest following strategy 2. This resulted in a further six people being recruited from the East and six from the West. At this stage, the screening questionnaire was no longer used for purposive sampling in terms of selecting participants on the basis of demographic characteristics, as all those who expressed an interest in taking part were recruited. Rather, the information gained from the questionnaires was used to assist with data analysis.

Strategy 4 involved pre-existing social groups from local community centres. The advantage of accessing pre-existing groups is that they are a ready-made sample with shared experiences and understanding therefore they are still considered homogenous (Barbour 2005, Gill et al. 2008). Permission was granted from the community centre managers and the facilitators of the social groups to approach the classes. On arrival to the groups, the attendees were provided with verbal and written information about the study and were requested to approach the researcher in another part of the community centre after their group had finished if they would like to take part in the study. This strategy was the most effective which achieved the recruitment of an adequate number of participants in order to complete public data collection. Table 3 outlines the focus group recruitment strategies and outcome. In total, eight public focus groups were conducted (four in the West of Scotland and four in the East of Scotland), consisting of 39 participants. Each focus group consisted of 4 – 6 people.

Table 3: Public focus groups and recruitment

Focus group and location	Number of participants in each focus group	Sampling strategy used
1: West of Scotland	6	Pre-existing social group
2: West of Scotland	4	Pre-existing social group
3: West of Scotland	4	Pre-existing social group
4: West of Scotland	6	Snowball sampling
5: East of Scotland	5	Response to newspaper article and snowball sampling
6: East of Scotland	4	Pre-existing social group
7: East of Scotland	6	Pre-existing social group
8: East of Scotland	4	Response from newspaper article and snowball sampling
39 participants		

Healthcare professionals

All healthcare organisations within both geographical areas were identified by an internet search and discussion with colleagues. From each website, contact details for the manager of the organisation were located and an email was sent explaining the study. Included with the email were a participant information leaflet (Appendix 6) and a request for their permission and assistance to approach their staff about taking part in the study. In the West, one acute hospital, one community hospital and one care home and in the East, one acute hospital and three community hospitals expressed an interest in taking part in the study.

Each manager of the healthcare organisations suggested that they would approach their staff to ask for volunteers and identify an appropriate day and to conduct the focus group. As gatekeepers are being increasingly used to

facilitate successful research participant recruitment (Shenton and Hayter 2004, Patterson et al. 2011), this was thought to be an appropriate approach. Table 4 outlines the focus group recruitment strategies. In total, seven healthcare professionals' focus groups were conducted (three in the West of Scotland and four in the East of Scotland), consisting of 29 participants. One focus group from each geographical setting included infection prevention and control practitioners (focus group 9 and 12). Each focus group consisted of 3 – 6 people.

Table 4: Healthcare professionals' focus groups and recruitment

Focus group and location	Number of participants in each focus group	Sampling strategy used
9: West of Scotland	3	Use of gatekeeper
10: West of Scotland	3	Use of gatekeeper
11: West of Scotland	6	Use of gatekeeper
12: East of Scotland	5	Use of gatekeeper
13: East of Scotland	5	Use of gatekeeper
14: East of Scotland	4	Use of gatekeeper
15: East of Scotland	3	Use of gatekeeper
29 participants		

Media professionals

Potential participants for the media professionals' interviews were initially identified from the media coverage analysis. As most newspapers stories are printed with the journalist's email address, contact was straightforward. Initially, 15 newspaper journalists were contacted by email and asked if they were interested in taking part in the study. A summary of the study and a participant information leaflet was also provided with the email (Appendix 7). Of the 15, four agreed to take part in the study, five responded to say they did

not feel they were in a position to take part and no response was received from six.

Through additional snowball sampling, those who initially agreed to take part in the study recommended people to contact and provided contact details. From this strategy, a further three participants were recruited. Additionally, snowball sampling from a colleague enabled an additional one participant to be recruited. Finally, following the researcher's attendance at a media workshop, two media professionals facilitating the workshop were approached and agreed to take part in the study. See Table 5 for an outline of interview recruitment strategies. In total, ten media professionals throughout the UK participated in this part of the study: nine as telephone interviews and one as a face-to-face interview (at the request of the journalist).

Table 5: Media professionals' interviews and sources of recruitment

Media professional interviews	Role	Sampling strategy used
1	Journalist	Response to initial email
2	Editor	Response to initial email
3	Journalist	Response to initial email
4	Journalist	Response to initial email
5	Journalist	Snowball sampling
6	Journalist	Snowball sampling
7	Journalist	Snowball sampling
8	Deputy editor	Media workshop
9	Journalist	Media workshop
10	Journalist	Snowball sampling
10 participants		

Data generation

Three qualitative data generation methods were used for this study: focus groups, in-depth interviews and media coverage. As explained in Chapter Three, triangulation in its true sense was not the aim of using mixed methods, therefore the focus groups and interviews were conducted as and when they could be arranged rather than sequentially. Prior to data generation, the researcher undertook a three half day training course which consisted of developing interview schedules and focus group topic guides and preparing for, and conducting, one-to-one interviews and focus groups. The training also provided the opportunity to practice conducting interviews and focus groups with research colleagues.

Focus groups

The majority of the public focus groups were conducted in community centre social rooms and HCPs' focus groups were conducted in staff rooms or quiet rooms within their workplace. Creating a relaxed ambiance and establishing a rapport with participants prior to the focus groups or interviews enabled the facilitation of a comfortable and open communication process. Thus it provided a basis for gaining more information and more meaningful insight from discussions (Dundon and Ryan 2010). This was established by a number of techniques. First, rooms were clean, warm, and made comfortable. Second, adequate time at the beginning of each focus group was made to welcome everyone and to allow for introductions. Third, light refreshments

were offered which provided the opportunity for everyone to engage in general conversation and make them feel at ease.

Once participants were seated and relaxed, further verbal information about the study was provided based on the participant information leaflet they had received. Further copies of the leaflet were also made available if required. Explanations were given as to their role and the researcher's role and the opportunity to ask questions was provided. All participants were asked to complete the screening questionnaire if they had not already done so prior to the focus group in order to obtain demographic information for analysis (Appendices 5 and 8), sign a consent form (Appendix 11) and place a name card in front of them. Participants were also reassured that confidentiality would be maintained, that they would remain anonymous and would not be identifiable in any subsequent report or paper. It also highlighted that their participation in the study was voluntary and they had the right to withdraw at any time, without explanation. Finally, all public focus group participants were offered £15 as a thank you for taking part in the study.

As participants are the key ingredient to a successful focus group discussion, it is customary that they should be thanked in some way. This can also be used as an 'enticement' for individuals to participate during the recruitment stage. What participants are offered is largely determined by the budget available. Most researchers, at the very least offer participants travel expenses depending on the location of the venue (Slomka et al. 2007).

However, others are less in favour of offering 'payment' to participants as it creates a culture of expectation which can be problematic for those who do not offer payment (Head 2009). Others also argue that offering money might inherently recruit only those from a more disadvantage demographic, thus leading to selection bias (Beckford and Broome 2007).

For this study, when initially approached, participants were informed that they would receive £15 for taking part. The range of participants in terms of professional and socio-economic status varied considerably, therefore payment did not appear to affect this. All participants were happy to accept the £15, with a number stating they would donate it to charity. Finally, prior to conducting each focus group, to ensure that all that everything was in order a tick-box check list was completed.

The focus group topic guides for both the public and the healthcare professionals consisted of seven very broad questions, each containing further probing questions (Appendices 9 and 10). These were informed by the research questions, methodological approach, the literature review, current theory and in-depth discussions with the researcher's supervisors. The questions were kept broad to enable more naturally occurring discussion rather than a moderator-dominated discussion, thus aligning with the purpose of conducting focus groups (Barbour 2007). Probing questions were kept as open as possible by using terms such as "*what do you mean by that?*" or "*can you explain a bit more about that?*" and bringing others into discussions by

asking “*what does everyone else think about that?*” Prompts however, were used with caution as Curtis and Redmond (2007) point out that they may have the potential to bias or orientate the discussion in a specific way.

An open dialogue between participants during all focus groups was fostered by allowing them to take control of the direction of discussion. Intervention by the researcher was therefore kept to a minimum and used only to guide participants along the focus of the study when discussions appeared to be going off track. Additionally, probing questions were tactfully directed at quiet or reluctant participants in order to balance out discussions and manage participants who tended to dominate. As full explanations were given prior to focus groups about respecting each other during discussions, dominating participants did not occur frequently.

Having expert knowledge of *C.difficile* enabled the researcher to better understand participants responses in addition to being able follow up on critical areas. For example, when participants spoke about technical issues around *C.difficile*, many were incorrect. This enabled the researcher to probe further to try to understand the reasons behind their perceptions. However, when doing this, it was important to recognise the potential risk of intentionally or inadvertently injecting personal or professional biases into participants' responses.

Notable differences between focus group discussions were identified. Some members of the public already knew each other or were friends or family and had attended the social group together so they often chatted about shared experiences. Unlike members of the public from the West, who chatted freely about many issues, those in the East were at times, more reserved and required a little more probing by the researcher. It was likely that this may have been because *C.difficile* did not have such a high profile in the East as it had in the West.

Ideally, when conducting focus groups, having another person attending as a note taker can be beneficial so that the researcher can give full attention to the discussion without the added role of taking notes about who is saying what and when, in addition to further observations of non-verbal language and group interaction (Barbour 2007). Mainly to the result of time limitations of colleagues and the geographical location of the focus groups, the researcher was unable to have a second person to take on the role of note taker. Instead, specific strategies were adopted to ensure data collection was not compromised. This included audio recording of each focus group, for which written consent was gained. This is common practice, especially for novice researchers as it permits full transcription of the discussion which can help enhance the quality of the data analysis and transparency process (DiCicco-Bloom and Crabtree 2006). Participants were reassured that audio recordings would be stored securely, only be accessible to the researchers and would be destroyed on completion of the study. No participants refused to consent.

Hand written notes during each focus group in terms of identifying who was saying what also proved to be very valuable during the transcription stage. For example, the name or initial of the person talking and the first few words were recorded. Additionally, any salient observations such as non-verbal language and group interactions/dynamics were also written down. Assisted by the name cards, a 'map' of who was sitting where, addressing participants by their names when asking any questions and noting the beginning of each sentence every time participants spoke was also valuable.

Immediately following each focus group, time was taken to reflect on the session in its entirety and extensive notes were written about any critical points that had emerged, observations of group dynamics, reflections of the researcher's role in conducting the focus groups and recording of issues that could be explored in further focus groups or interviews. This captured immediate reactions and helped to recall emergent patterns during the analysis. This was then synthesised onto a contact summary sheet (Miles et al. 2014) (Appendix 12). Finally, audio recordings were transcribed verbatim as soon as possible after the focus group.

At the end of each focus group, the researcher thanked all participants for taking part and explained how the study would progress. It was also explained that the intention would be to publish findings and that any publications would be referenced on the researcher's professional profile, should they wish to

access a copy. The researcher also remained at the focus group setting until all participants had left to be available to answer any questions.

In-depth semi structured interviews

Owing to the geographical location and unpredictable work demands of media professionals, the majority of interviews (n=9) were conducted via the telephone. The one face-to-face interview was at the journalists request and was conducted in a quiet room within the researcher's workplace. Each telephone interview was conducted in the researcher's work office with a 'do not disturb' sign on the door. Having no face-to-face contact with the participants meant interaction that would normally occur prior to the interview could not be achieved. However, through email and telephone contact during the recruitment stage, a rapport was established. Small talk was also made at the beginning of the telephone interview to allow participants and the researcher to feel at ease.

Verbal information about the study was provided prior to the interview starting and there was a discussion about the participant information leaflet which had been provided via email during the recruitment stage. The consent form was also emailed prior to the interview and was signed and either returned via the post or email. Similar to the focus groups, assurances were given that confidentiality and anonymity would be maintained and they could withdraw from the interview at any time.

All interviews were audio recorded by using a speaker phone and placing the digital recorder beside the telephone for which written consent was obtained. In addition to audio recording, the researcher made hand written notes during the interview to record salient observations and thoughts. Although recording most non-verbal communication was impossible with telephone interviews, silences, pauses, voice tones and reactions were noted. In interpretive research, silences can be profoundly meaningful therefore are an important, albeit often overlooked part of the data (Novick 2008). They can indicate that the participants are simply thinking about something in relation to what they are saying, or that the participant is feeling uncomfortable about something, the participant is bored or they have simply finished saying what they wanted to say. By gauging what the silence may mean the researcher is guided to decide whether to allow the silence to continue or to interrupt the silence. To overcome this, the silence was allowed to continue for a short period of time, followed up by a short probing question.

The development of the interview schedule was informed by the research questions, the literature and discussion with other researchers and consisted of seven broad questions in addition to some probing questions, without being directive (Appendix 13). Questions were kept broad as it was important to achieve a naturally flowing conversation and allow the participants to portray their perspectives in their own words. This enabled participants to talk freely about their views and experiences with minimal interruptions from the researcher.

At the end of each interview, participants were thanked for their participation in the study. They were also advised that any future publications would be placed on the researcher's university profile which they could access. As with the focus groups, extensive notes were written immediately following the interview to record major themes, ideas and concepts and observations, then synthesised onto a contact summary sheet and the interviews were transcribed verbatim as soon as possible.

Data analysis planning

The purpose of developing a robust data analysis plan was to ensure that the researcher could delineate boundaries of the analysis and have a clear understanding of the principles that needed to be followed when making sense of the data. A data analysis plan is especially important in ID methodology so that the research moves beyond purely description to achieve an acceptable level of interpretation and abstraction (Hunt 2009). A robust plan, therefore, helped project ahead to the analytical steps that needed to be taken in order to address the research questions (Thorne et al. 2004). Without such a plan, the researcher can become overwhelmed by the sheer volume of data which could result in disparities between the research questions, findings and interpretations (Li and Seale 2007).

Although much of the qualitative research literature highlights the importance of having a robust data analysis plan (Seale et al. 2004, Silverman 2011, Miles et al. 2014), there are limited examples of what such a plan looks like or even

guidance on how to develop one. As a result, guided by the principles of data analysis in ID and discussions with research experts, a data analysis plan was developed (Appendix 14) which addressed the following key questions:

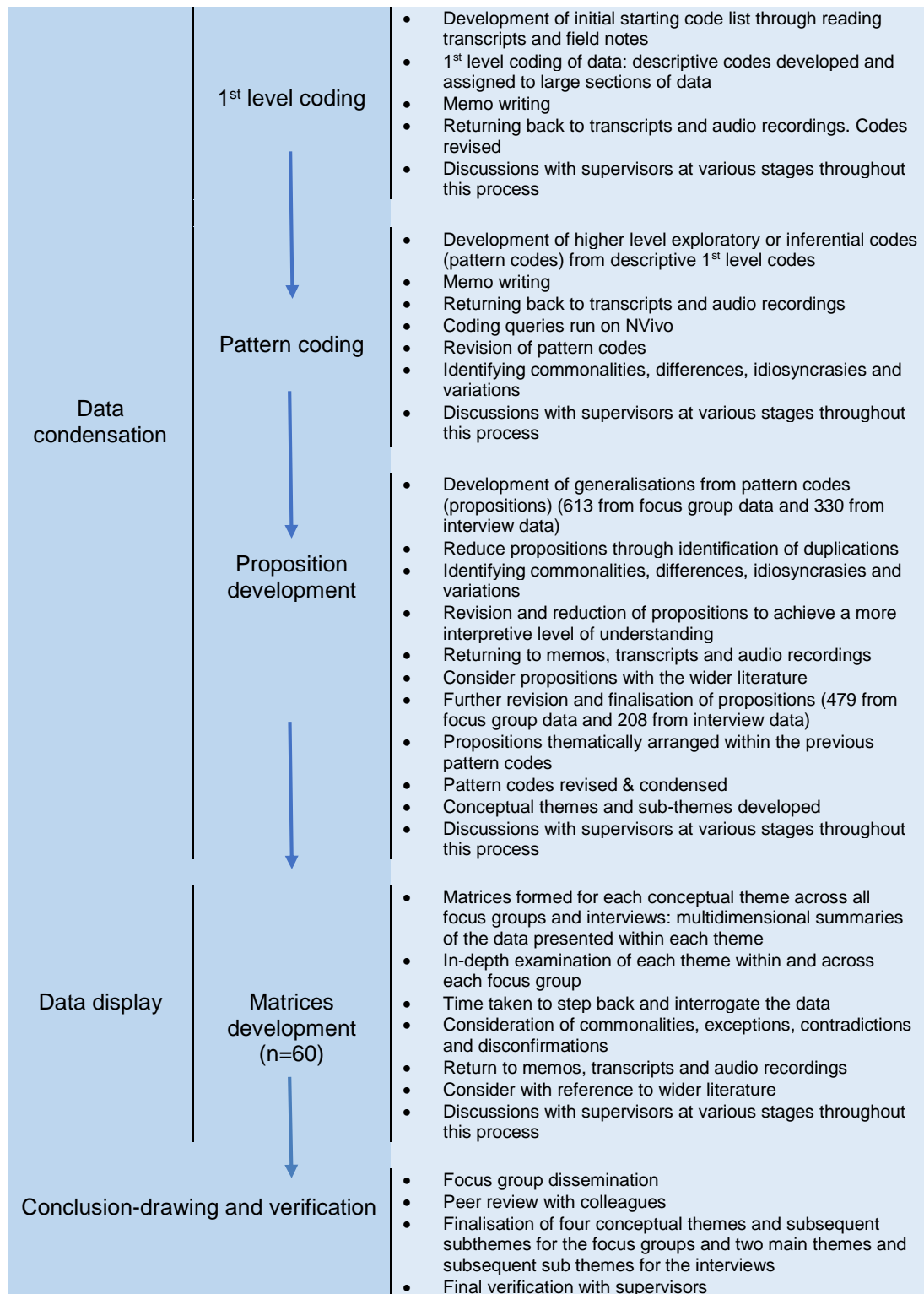
- What are the research questions?
- What is the analytical purpose?
- What is the practical purpose of the analysis?
- How is the analysis of the data sets connected to the research questions?
- What needs to be asked of the data?
- What framework and tool(s) will be used to help conduct the analysis?
- What resources will be needed to conduct the analysis?
- How is the data going to be presented?
- What is the timeline for analysis?

Informed by the philosophical and methodological approach, the research questions and through in-depth discussions with the researcher's supervisors, it was decided that the public and HCP focus groups would be analysed together and the media professional's interviews separately. This decision was made because the questions being asked of the public and HCP data were similar in terms of exploring risk perceptions and responses. Moreover, by analysing them together, it allowed the data to be interrogated for commonalities and differences more effectively. The research question relating to the media professional's interviews differed from the public and

HCPs therefore the interview data required to be analysed separately and was conducted after the focus group data analysis.

Analysing the focus group and interview data

Using the main data analysis components developed by Miles et al. (2014): data condensation, data display and conclusion-drawing and verifying, various approaches were used to assist with the focus group and interview data analysis. Using these approaches enabled a rigorous, transparent and auditable process which helped achieved the level of exploration and interpretation appropriate for ID methodology (Thorne 2008). As there were two large and diverse data sets to analyse (focus group then interview data), the data analysis process was challenging and took a considerable amount of time to complete. The processes for analysing each data set was iterative in that it was necessary to move back and forth through each stage to ensure that a full, in-depth analytical and interpretative approach was achieved (Silverman 2011). Figure 6 presents a schematic summary of the iterative data analysis process adopted for this study. This process was undertaken twice – first for the focus group data then second for the interview data.

Figure 6: Analytical process

Preparing the data

The process began by transferring the audio files onto a password-protected computer to allow for transcription. Whilst some suggest that verbatim transcription of qualitative research data is not always necessary (Halcomb and Davidson 2006), Oliver et al. (2005) point out that transcribing is a powerful and important act of representation and can affect how data is conceptualised. Although the focus groups and interviews generated copious amounts of data and took a substantial amount of time to transcribe verbatim, it was a crucial part of data analysis. During this stage, early thoughts about what was happening in the data occurred and initial themes and concepts began to emerge. Indeed, some conceptual thoughts that arose during transcription continued through to the end of the analysis process.

Thoughts were recorded in memos so that they could be used for reference at a later stage. When transcribing, every word the participants said was recorded, including fillers such as “um”, “er” and “ah”. Additionally, silences, pauses, laughter and coughs and non-verbal language such as nudging, smiling, eye rolling and looking away from the group recorded during the focus groups were also included in the transcription. As far as possible, similar responses from the telephone interviews were also included. This provided insights into the thinking processes of the participants during analysis. Colourful language, slang words, grammatical errors and mispronunciations were also recorded to help highlight emotion, added meaning to spoken words and to ensure participants own words were used to tell their story. Each

transcription was then read and re-read to enable complete immersion in the data. During this time, audio recordings were also listened to a number of times.

To maintain anonymity, all participants were assigned pseudonyms. It was felt that using pseudonym rather than only numeric or alphabetical codes brought the participants 'to life'. To help with this, care was taken to give pseudonyms that were of similar character to the participants own name (Saunders et al. 2014). For example, it was not seen as appropriate to assign a 'Chantelle' to a 'Margaret'. Codes however were also required in order to differentiate between the public and healthcare professionals and geographical location. Each participant taking part in a focus group or one-to-one interview were numbered from 1 – 78 beginning with the public, then healthcare professionals then media professionals. Table 6 illustrates how codes were assigned.

Table 6: Assignment of codes for participants

Participant	Code
Member of the public in focus group 1 in the West of Scotland	PW1-1 (Public; West) and the 1-1 being focus group 1 - participant number 1
Member of the public in focus group 5 in the East of Scotland	PE5-21 (Public; East) and the 5-21 being focus group 5 – participant number 21
Healthcare professional in focus group 9 in the West of Scotland	(HW9-40) (Healthcare; West) and the 9-40 being focus group 9 – participant number 40
Healthcare professional in focus group 12 in the East of Scotland	HW12-53 (Healthcare; West) and the 15-66 being focus group 12 – participant number 53
Media professional	M-69 (tabloid) (Media; participant number 69). (worked for a tabloid newspaper)

Transcriptions were then prepared to be imported into NVivo 10 for data management. Each transcript was presented in the same format and style and all headers and footers were removed. All participants' names were entered into a nodes folder to enable attributes or characteristics to be assigned to them. These were obtained from their demographic questionnaires that were completed prior to the focus groups and interviews. This allowed for in-depth exploration of the data in relation to exploring themes, similarities and differences among participants later on in the analysis.

Computer assisted qualitative data analysis software (CAQDAS) such as NVivo can assist with the facilitation of an accurate, reliable and transparent data analysis process through coding, searching, indexing, analysing, synthesising and presenting data (Goble et al. 2012). Such programmes are especially helpful with managing large amounts of data as they can be broken down into manageable components which are easily retrievable, thus increasing the efficiency of access to the data (Baheiraei et al.). Another advantage of using CAQDAS is it enables a comprehensive record of major analytical decisions and revisions made by the researchers and provides a clear audit trail, thus enhancing rigour of the analysis process (Leech and Onwuegbuzie 2007).

Disadvantages of using CAQDAS however are also recognised. Lu and Shulman (2008) suggest that due to the enhanced capabilities of dealing with large data sets, researchers may be inclined to focus more on raw quantity

rather than meaning. Others also argue that researchers run the risk of not really getting to know their data or becoming distant or decontextualised from it (Bringer et al. 2006). Consequently, when deciding whether or not to use CAQDAS for this study, it was crucial that careful consideration was paid to how useful it would be, how it could be used effectively within existing analysis methods, and what software would be used. The most important factor however, was that the function of CAQDAS was not to eliminate the need to think and deliberate or to conduct the interpretation of the data. Rather it was to provide an efficient means through which to manage and organize data while supporting rigorous analysis (Banner and Albarran 2009).

NVivo 9 and 10 was used for this study, in conjunction with manual analysis. This decision was taken because there were four large data sets to work with which would have been too substantial to be able to manage manually. Additionally, using this software helped to enabled trustworthiness and rigor to be demonstrated. To help with this, the researcher attended a two day NVivo course facilitated by QSR International.

The following section outlines the data analysis process. As this process was used for both the focus group and interview data, it was undertaken on two separate occasions. First for the focus group data, then again for the interview data. Throughout the analysis of the focus group data, while there were effectively two different groups of participant data being analysed, they were managed as one data set. While the context of discussions clearly differed

between the public and HCPs, analysing them together did not cause any problems as the research questions were seeking to explore *how* and *why* they perceived and responded to risk factors they associated with *C.difficile*. For example, in Appendix 17, one of the subcodes of a pattern code was 'fear'. While the context in which fear was experienced was different i.e. the public were fearful for their own safety while in hospital and HCPs talked about why they thought patients are fearful of *C.difficile*, the overarching theme was still similar for both groups. The data analysis plan in Appendix 14 demonstrates the consideration of questions that needed to be asked of all focus group data in order to address the research questions.

Data condensation: 1st level coding

For the focus group data, a broad initial starting code list was developed from field notes taken immediately after the focus groups and the literature previously reviewed. This list was entered as *a priori* nodes to assist with the 1st level coding, as part of data condensation. The primary function of data condensation is to select, focus and simplify the raw data into manageable chunks so the researcher can become familiar with and immersed in the data and begin to make sense of them (Rabiee 2004). These codes were listed on a coding framework and a clear operational definition was developed to enable a clear understanding of what type of data could be assigned to each code (Appendix 15). This coding framework also illustrates how the focus group data from both the public and HCPs were coded together. No starting code list was used for the subsequent interview data because owing to the nature

of the research question, it was more appropriate to allow themes to emerge inductively from the data. Rather, a first level coding sheet was developed during the re-reading of the interview transcripts and listening to the audio recordings (Appendix 16).

Each NVivo imported transcript was read and re read, then the data was grouped into chunks or sections within the initial descriptive codes, making sure that participants' language was retained as much as possible. During this stage, some codes were revised or removed and additional codes and sub codes were created as new themes emerged. As codes were revised, the iterative process of re-reading transcripts and further coding continued. The creation of memos took place simultaneously with coding so that thoughts, ideas, and puzzling and surprising concepts could be recorded. This helped to gain a more coherent, conceptual sense of what was happening which was then be returned to later on in the analysis.

Data condensation: pattern coding

First level coding was followed by pattern coding which condensed the data further through the development of explanatory or inferential codes from the initial codes. These pattern codes can be in the form of themes, causes and explanations, relationships among people and more theoretical constructs. Miles et al. (2014) refer to this as meta-codes as a lot of material is pulled into more meaningful and harmonious units of analysis. Others refer to this process as categorising (Thomas 2003, Ritchie et al. 2003). The purpose of

pattern coding was not to achieve closure, but a prelude to further analysis in terms of helping identify commonalities, differences, idiosyncrasies and variations (Miles et al. 2014). To do this, the data were examined carefully to focus on the meaning of the data and a number of questions were asked such as: What is happening here? What is trying to be conveyed? What are the similarities? What are the differences? (See Appendices 17 and 18 for final pattern coding templates).

During the data condensation process, to prevent the researcher from becoming overwhelmed and lost, memoing continued so that evolving thoughts, ideas and insights could be returned to as analysis progressed (Miles et al. 2014). Furthermore, to assume a reflexive stance and ensure credibility, memoing also provided a formal mechanism whereby perspectives could be recorded for later critical review or confirmation (Birks et al. 2008).

Data condensation: proposition development

While memoing enables researchers to capture their thoughts as coding progresses, once pattern codes have been determined, further work was required in order to formalise and systematise thinking into a coherent set of explanations. This was achieved through the development of propositions and provided some generalisations to be made about statements within the pattern code. This enabled the researcher to begin to understand and make sense of what was happening in the data (Thorne 2008). It was during this process that

analysis was then able to begin to move beyond descriptive to more of an interpretive level.

While developing propositions, original transcripts were often referred to in order to ensure the propositions reflected participants' accounts. A total of 613 propositions were initially developed from the public and HCP focus group pattern codes. These were reduced to 479 following a number of iterations of sorting, revision and removal of duplication. For the media professional interviews, a total of 330 propositions were developed, which were then reduced to 208. The propositions were then sorted and placed under main conceptual themes and subthemes. Some of these themes and subthemes aligned with some of the previously developed pattern codes, but additionally, other conceptual themes and subthemes emerged. This process was undertaken manually using flip chart paper and post-it notes so that the data could be visualised as a whole on a larger canvas. This enabled more time and space to explore and examine the propositions, link commonalities and differences, return to the literature and take time to think, reflect and be creative. During this process, transcripts and memos were returned to and the wider literature was consulted, in addition to regular discussions with supervisors. After a number of reiterations, the final propositions were then thematically arranged within the final conceptual themes and subthemes.

Data display: matrix development

Following proposition development, in order to then start to make sense of the data, visual displays were developed. These provided a way in which the data could be organised, summarised and simplified (Richards 2005). Additionally, it allowed enhanced reading and comprehension of data and provided a robust way in which to promote transparency of the data analysis process (Verdinelli and Sagnoli 2013). However, Hunter et al. (2002) highlights that displaying data can be a very laborious process as it requires incubation time so that creativity can be illuminated. Additionally, they point out that there are no right or wrong ways to use visual displays. Indeed, some researchers may not be 'visually' orientated and therefore favour the more traditional textual data displays. Data can be displayed in many forms, such as matrices, flow charts or decision trees, all of which has their own purpose (Richards 2005, Verdinelli and Sagnoli 2013).

For this study, matrices were used. They consisted of defined rows and columns which helped to form a multidimensional summary of the data in order to carry out detailed analysis and interpretation. According to Miles et al. (2014), they are particularly effective for combining parallel data from single cases or combining data from several cases. Thus, they allowed interrogation of the themes both within and between all focus groups and interviews. Additionally, they are the most commonly used method for interpretive qualitative research. Miles et al. (2014, p.113) describe matrix construction as

“a creative yet systematic tasks that furthers your understanding of the substance and meaning of your database”.

For each main theme developed during the proposition development stage for both the focus group data and the interview data, a matrix was created which included the subthemes. For the public and HCP focus group data, as four main themes were finally developed and 15 focus groups were conducted, 60 matrices were created (one matrix per focus group for each theme). The creation of matrices for the media professionals' interview data was a little more straightforward. As these were one-to-one interviews, each of the ten participants were entered onto one matrix per theme, therefore two matrices were developed (one matrix for each theme).

While creating the matrices, it was important to:

- Include sufficient detail that was understandable and not overly cryptic
- Retain participants language
- Include short verbatim excerpts if necessary
- Include researcher's commentaries about context and focus group interaction

This final process of data analysis enabled much more insight into what the data was saying and what it was not saying, commonalities, differences, the unsurprising and the surprising. It was, however, difficult to jump back and

forth across so many matrices on a computer screen so the matrices were uploaded into excel, printed out and attached to flip chart paper. During this time, the matrices were read and re-read while returning back to the literature, memos, audio recordings and initial transcripts.

Conclusions: drawing and verification

As data analysis progressed, the focus on description moved towards interpretation and conclusion-drawing, and verification took place. In order to draw conclusions, the researcher ‘stepped back’ to consider what the data meant in terms of the questions being asked. During this process, Barbour (2014, p. 271) encourages researchers to spend some time to “*worry away*” at the data whereby he/she engages in interrogation of the categories in order to identify and consider commonalities, exceptions, contradictions or disconfirmations. In doing so, particular attention is paid to who is saying what and in which context and how this relates to what is already known (or not known). Verifying is integral to conclusion drawing in terms of cross-checking or verifying these emerging conclusions.

At this point, it was helpful to return to the initial patterns, themes, memos, propositions and to reflect on the research journal. During this period of time, care was taken around the interpretation of the data. Generalised utterances observed during qualitative data collection methods can perform other functions rather than offering explanation to underlying rationales associated with risk (Barbour 2007). For example, in relation to the occurrence and

spread of *C.difficile*, utterances such as “*the doctors are the worse*” or “*those nurses aren’t nurses anymore*” could also be ways of participants recruiting members of the focus group to a commonality rather than illustrate any risk evaluation or judgement. In other words, they could be simple rhetorical tropes utilised to keep conversation going. Such comments, therefore, needed to be considered in light with other dialogues. During the focus groups within this study, however, the conversations generally flowed freely and easily and although many commonalities were shared, participants did not seem to be concerned about offering alternative views. Any generalised utterances therefore were believed to be connected to their perceptions about *C.difficile* rather than for any other reasons.

This whole process enabled the finalisation of the study’s themes and subthemes. For the focus groups, this consisted of four main themes and various subthemes (Table 7) and for the interviews this consisted of two main themes and various subthemes (Table 8). Additionally, fitting with qualitative research, the research questions were able to be refined a number of times during the course of the data analysis so that they were clear, concise and aligned with the findings of the study (Braun and Clarke 2006).

Table 7: Public and healthcare professionals' focus group findings

Main themes	Sub-themes
<i>Being vulnerable</i>	<i>"Consequential fear"</i> <i>"Being in the firing line"</i>
<i>Attribution of responsibility</i>	<i>"Questioning attitudes, knowledge and skills"</i> <i>"Not like the good old days"</i>
<i>Making sense of competence</i>	<i>"Doing the right thing"</i> <i>"Being reassured"</i>
<i>Evaluations of the communicators</i>	<i>"The media: the bleak, the bad and the miserable?"</i> <i>"The experts: to trust or not to trust?"</i>

Table 8: Media professionals' interview themes and subthemes

Main themes	Sub-themes
<i>Role in health-related risk reporting</i>	<i>"To report or not to report"</i> <i>"Analyse, probe and uncover"</i> <i>"Making the complex simple and memorable"</i>
<i>Challenges and constraints</i>	<i>"Getting the right information, from the right people, at the right time"</i> <i>"Whose agenda?"</i> <i>"Competing with others"</i>

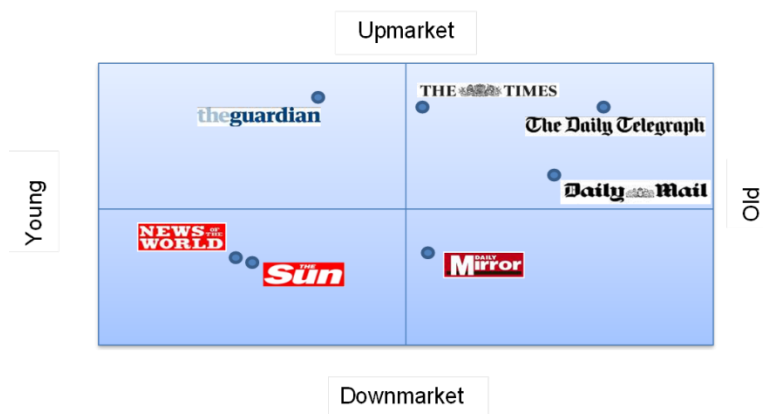
Throughout the whole data analysis process every effort was made to stay true to participants' views and accounts and not to misrepresent them in any way. Additionally, from a weak social constructionist perspective, the focus of data analysis was to understand multiple realities rather than a single reality or truth and acknowledge that no individual account was viewed as right or wrong or better than another.

Media coverage analysis

Using the online database LexisNexis®, 28 original newspaper articles pertaining to the Vale of Leven Hospital *C.difficile* outbreak were included in the media coverage analysis. A sampling pool of all national broadsheets, tabloids and Sunday papers was generated to allow for purposive sampling (Appendix 19). From the sampling pool, purposive sampling identified three national broadsheet daily newspapers (*Daily Telegraph*; *Guardian*; *Times*), three national tabloid newspapers (*Daily Mail*; *Daily Mirror*; *The Sun*), a Sunday newspaper (*News of the World*), and a regional newspaper (*The Herald*) to be included in this study. These newspapers were chosen first to reflect the broad political shades of opinion, highbrow/lowbrow spread and readership of the UK newspapers (recorded in 2010) (Figure 7) (Newspaper Marketing Agency Ltd 2003). This also addressed the concerns of Boykoff (2008), who criticises researchers who include media coverage in their research for frequently focusing mainly on broadsheet sources, despite readership figures for tabloids being almost ten times higher. Finally, a

Sunday newspaper was also included as they tend to have longer articles and features and are often more analytical (Washer 2006).

Figure 7: Sample readership by age and social class



The snapshot of coverage analysed was for a three week period from the first day the story appeared in newspapers (12th June 2008 - 3rd July 2008). Inclusion dates were selected to enable an appropriate amount of coverage to gain an understanding of how *C.difficile* was represented and how reporting changed over time, given that outbreaks usually evolve fairly rapidly. The following search terms were entered into LexisNexis®: *C.difficile*; C.diff; healthcare associated infection; hospital acquired infection; superbug; Vale of Leven. Some of these terms reflect the various euphemisms often used for *Clostridium difficile* and were included to ensure no relevant stories were missed. An inclusion criterion of coverage was adopted from the framework developed by Lynch and Peer (2002) as it reflected what was required to capture the essence of the outbreak coverage. Each article:

- must be longer than two inches in length
- must be written in complete sentences that included a central theme (*C.difficile* and Vale of Leven Hospital outbreak)
- must not be part of a paid advertisement
- must not be a promotional reference for a full story that is contained elsewhere, therefore they must be a complete story

The search yielded 28 newspaper articles, all of which were included in the analysis. As pointed out by Gunter (2000), qualitative analysis of textual content is primarily about the location of meaning. In order to achieve this, analysis began by reading and re-reading of each of the included media articles. This allowed the researcher to become familiar not only with each individual newspaper story but also to gain an initial insight into how these stories changed over time. Following the familiarisation phase, each newspaper article was assigned an identification number and a coding template consisting of a number of broad categories and themes within each category, was developed. This enabled the reduction of the volume of data to more manageable concepts aligning to the aim of the analysis (Barbour 2014).

The template was based on a previously validated coding template used for a number of similar media coverage analyses to aid the exploration of media representation of a specific health related risk (Kitzinger and Philo 1999, Kitzinger 2000, Kitzinger 2008). This helped ensure that the relevant study aim and questions were being addressed and to help enhance rigor and

credibility in terms of transparency and auditability. Each category was allocated a definition (clear statement of what it was) and a description (how to know when it occurs in the newspaper article). The coding form was piloted with five newspaper articles which were not included in the study sample. These newspaper articles were from a previous highly publicised outbreak in a different part of the UK therefore they were similar to the newspaper articles included in this analysis. Minor revisions were then made. The final coding template consisted of ten categories and a number of themes (Appendix 20). The categories consisted of: headline; story type; statistics; sources; terms used; affected patients; causes; blame; solutions and overall impression. Descriptive summaries congruent to each category were then manually entered onto a coding template for each included newspaper article. Two other researchers independently checked 20% of the included coded articles to test reliability and minor differences of opinions were resolved through in-depth discussion.

The coding templates and original newspaper articles were then imported into NVivo 9 to enable further exploration and interrogation of the data. This was a fairly lengthy process which not only involved moving back and forth between the coding templates and the original newspaper articles, but also involved 'stepping back' and spending time reflecting on the data. As a result, the original categories and themes were developed into four main themes and a number of subthemes.

The next stage of the analysis was to move beyond descriptive analysis and explore patterns, relationships and possible explanations (Richards 2005). In order to achieve this, a framework matrix for each theme then a final master framework matrix was created. This allowed for the data to be synthesised while retaining a direct link back to the original data, compare both within and across each theme and also within the whole data set (Ritchie et al. 2013). This method enabled the researcher to move beyond simple categorisation and coding and explore relationships between them.

It was during this process that there emerged a sense of a storyline, which almost seemed like a fictional drama whereby individual characters are created and re-created as the outbreak progressed. This led the researcher to return to specific risk, and media and risk literature (Seale 2004, Seale 2006, Seale 2010). Seale's work points out that media representation of risk usually contain key elements: the dangers of modern life, villains and freaks; victimhood; professional heroes and lay heroes. He goes on to explain that the media are key in representing specific health issues and individuals that are seen as important associations of these health issues. As a result, it is necessary to understanding how individuals are characterised in the media in order to understand how the media audiences may relate to media coverage. From the framework matrices formed, it was apparent that *C.difficile* and key individuals had been created and re-created as certain characters throughout the coverage, therefore Seale's work informed the development of the final

two main themes and various subthemes from the media coverage analysis (Table 9) (Burnett et al. 2013a).

Table 9: Media coverage analysis themes and subthemes

Main themes	Sub-themes
<i>Constructing C.difficile</i>	<i>"C.difficile as a war"</i> <i>"C.difficile as a monster"</i>
<i>Constructing identities</i>	<i>"Victims"</i> <i>"Villains"</i> <i>"Heroes"</i>

Ethical considerations

In any health research, rights-based approaches are used in which ethical decisions are made on the basis of the consequences or outcomes of research participation (Wiles et al. 2005, Seale 2012). Despite their age, four main principles set out by Beauchamp (1994) remain regarded as the working foundation for ethics: beneficence, non-maleficence, autonomy and justice.

Beneficence and non-maleficence

The principles of beneficence and non-maleficence are fundamental to all research activity. Central to beneficence is the researcher's responsibility to provide benefits and to assess the balance between the benefits and risks. In other words, beneficence is a researcher's basic obligation to do good. Non-maleficence is concerned with doing no harm (Beauchamp 1994).

Researchers have an obligation to take appropriate action so that risks of harm to themselves and others are minimised.

To maintain the principle of beneficence and non-maleficence, all participants were provided with in-depth written information which contained the researcher's contact information should they have any questions or wish to discuss any aspect of the study further. This information was reiterated immediately prior to the focus groups and interviews to ensure it had been understood and the opportunity to ask questions was provided. It was also made clear to all participants that they were under no obligation to continue to take part in the study and that they could withdraw at any time without explanation. No participant withdrew at any time throughout the course of the research.

Another crucial aspect of beneficence and non-maleficence is ensuring that participant's identities are not revealed. Pseudonyms were therefore assigned to all participants and each participant was informed that no personal information would be used which would identify them. All transcripts and field notes were stored securely on a password protected personal computer which was not used by any other individual apart from the researcher. All audio recordings will be erased following completion of this study. Additionally, field notes, participant questionnaires and consent forms are locked in a filing cabinet which no other individual has access to and data will be stored for one year before being destroyed.

Autonomy

Personal autonomy is concerned with allowing participants to control what happens to them during the research and ensuring their dignity is respected at all times (Beauchamp 1994). This principle was honoured by informed consent so that participants were able to exercise their rights to voluntarily agree to participate in the study and were not coerced in any way (Orb et al. 2000). The purpose of informed consent was to ensure that participants had a clear understanding, after full explanation was given, of what participation would involve, what their rights were in relation to participation and issues of confidentiality and anonymity (Wiles et al. 2005).

Before informed consent was requested, all participants were provided with in-depth verbal and written information and the opportunity to ask questions at any time through the course of the study. Informed consent was also obtained for all focus groups and interviews to be audio recorded and reassurance was given that the recordings would only be used for transcription and analysis purposes. Additionally, participants were notified that even after providing informed consent they were still able to withdraw at any time without any explanation and were able to retract anything that they said during the focus groups or interviews. Prior to each focus group, participants were reminded about the importance of respecting each other and their confidentiality and privacy.

Justice

Justice refers to the researcher's obligation of fairness in the distribution of benefits and risks (Beauchamp 1994). Critical to this is ensuring that the participants are not exploited or abused in any way. The researcher applied the principle of justice to this study by ensuring that all participants understood the purpose of the study through verbal and written communication and that they were able to withdraw at any time without the need to provide an explanation. Furthermore, the researcher often relayed participant accounts and positions during the discussions to ensure they had been understood and interpreted correctly.

Justice in qualitative research is demonstrated by recognising the vulnerability of participants (Orb et al. 2000). As identified previously, given that *C.difficile* has had a significant impact on morbidity and mortality, especially in the West of Scotland, the researcher was aware that some members of the public or healthcare professionals may have had personal experiences which could potentially cause anxiety and distress. To address this, establishing a relationship with participants prior to focus groups helped create a safe environment and gain their trust at the onset. All participants were reassured that they were in a safe environment and could stop or retract their contribution at any time. Furthermore, as the researcher is an experienced infection prevention and control practitioner, if anyone wished to speak in private or in confidence after the session they were able to do so. However, no participant

became distressed or upset in any way and no-one requested to stop discussions or retract any contribution.

The interpersonal dynamics of a homogenous group (in this case, living in a community affected by *C.difficile*) enabled participants to gain mutual comfort and reassurance, thus encouraging them to enter into safe extended discussion and debate (Jordon et al. 2007). Within all focus groups, participants were keen to talk about, share and compare their experiences. A number of participants also stayed behind after sessions to ask generic questions about *C.difficile*, which the researcher was able to answer with ease. National information leaflets were also provided for this purpose.

Trustworthiness and rigor

Due to the subjective nature of qualitative research, specific constructs need to be applied to demonstrate trustworthiness and rigor. According to Dixon-Woods et al. (2004), in order for qualitative research to make a valuable contribution to healthcare, such criteria which determine the quality of qualitative studies is crucial. This study adopted a four criteria construct developed by Lincoln and Guba (1985a), which continues to be widely used and promoted by interpretive qualitative researchers (Silverman 2011, Seale 2012, Barbour 2014). These are constructs are credibility, transferability, dependability and confirmability.

Credibility

Credibility is concerned with giving the reader confidence that an accurate interpretation and presentation of the participants' reality has been provided (Thomas and Magilvy 2011). Within this study, credibility was established through a number of ways. Firstly, as qualitative research by nature lends itself to varying degrees of subjectivity, the researcher's own assumptions, views, experiences and behaviour were continually acknowledged and reflected upon through reflexivity. Signposts were provided about what happened throughout the study and why certain decisions were made so that any subjectivity was made transparent (Bradbury-Jones 2007). Additionally, a research journal was kept from the start of the study, and entries about challenges faced and decisions made were documented regularly. A public blog via WordPress was also created and new entries about the research process were posted regularly. Comments and feedback were often made about posts by other academics and researchers from wide and diverse backgrounds which encouraged further discussion and reflection. Each new blog was also linked to the researcher's Twitter account to allow for a wider reach. Engaging in social media this way allowed for a degree of peer examination and further reflection (Reid and Gough 2000).

Transferability

Due to smaller sample sizes in qualitative research compared to quantitative research, generalisability in its true sense is not the ultimate goal. Qualitative researchers focus more on transferability whereby every effort is taken to

ensure that the findings of the study in one context can be transferred to other contexts (Shenton 2004, Seale 2012). To address this, sufficient contextual information about the processes and decisions taken throughout the study is provided. This enables the reader to determine whether or not they are confident in being able to make the transfer. Additionally, in-depth description of the phenomenon under investigation is provided to allow readers to gain a sound understanding of it so that they can make comparisons with the phenomenon in their situation.

Dependability

Dependability refers to the degree to which the research processes are documented in order to allow the reader to follow and critique the study (Lietz and Zayas 2010). To enhance dependability, the auditability of the research was considered important. This was achieved by ensuring all data, both written and audio was kept and stored safely. Additionally, the researcher's journal enabled the provision of a regular written account of what happened during the research and subsequent decisions that were made, thus also drawing on reflexivity. Peer debriefing was also important whereby the researcher met with and consulted her supervisors and other researchers regularly throughout the duration of the study to discuss various aspects of the research. Detailed written accounts of all meetings with the researcher's supervisors were produced, thus providing an understanding of important feedback.

Confirmability

Confirmability corresponds to objectivity in quantitative research although they differ as qualitative researchers are more concerned with subjectivity. However, both defend neutrality in that the research cannot distort the reality it set out to describe (Sinkovics et al. 2008). From a qualitative perspective, researchers must use strategies that are adopted to ensure, as far as possible that the findings are the product of participants input rather than the characteristics and preferences of the researcher (Shenton 2004). Common strategies adopted by qualitative researchers to ensure confirmability include auditing, peer debriefing and member checking (Bowen 2005, Carcary 2009).

Auditability in qualitative research considers the matter of consistency. The researcher must therefore maintain a record of data management techniques, methods, processes and decision-making so that a chain of evidence can be developed (Miles et al. 2014). This documentation can then be examined and clearly understood by a researcher or reader. All data information and documentation for this study was kept securely, including audio recordings, transcripts and field notes. Additionally, regular in-depth discussions were conducted with the researcher's supervisors during throughout the data analysis process. Access to all analytical documentation via NVivo was also available to supervisors. Finally, the researcher's journal recorded processes and decision making at regular points throughout the study.

Peer debriefing can occur in a variety of ways and enables the researcher to conduct external evaluations of the research process. Onwuegbuzie et al. (2008) note this as essentially being another form of intercoder reliability but rather than empirically based, it is logically based. In peer debriefing the researcher meets with other researchers so that the research process and study findings can be critically reviewed and feedback can be given regarding the transparency, appropriateness and completeness of the study (Long and Johnson 2000). This, as highlighted by Lincoln and Guba (1985b), provides an external check on the inquiry process in order to ensure a high quality credible study is produced.

Throughout the entire course of the study, there were regular discussions with supervisors and other researchers. Additionally, various aspects of the research study, both from a methodological and topic perspective were presented in a variety of ways from local fora, seminars, symposia, to national and international conferences. Presenting in these types of ways fostered further discussion and questioning and valuable feedback was gained. Three academic papers were published in well known, quality, peer reviewed journals (Burnett et al. 2012, Burnett et al. 2013b, Burnett et al. 2013a), one of which was reviewed as part of a journal watch in another peer review journal (Wigglesworth 2013). Finally, at the end of each blog post published about the research process and decisions made, the researcher purposively invited questions, comments and feedback from interested parties.

Member checking

Member checking has been considered as a robust quality control process whereby the researcher seeks to improve the accuracy and validity of their findings and interpretation (Harper and Cole 2012). This is also referred to as participant verification (Morse et al. 2002) and respondent validation (Torrance 2012). However, others refute this. Goldblatt et al. (2011) point out that member checking is a controversial procedure, extremely complex and rather than being an effective method for achieving credibility, can cause ethical as well as practical problems. For example, if conducted remotely, verbatim transcripts are often sent to participants, which could cause a breach of privacy and upset if they were accidentally sent to wrong participants. Participants may also feel uncomfortable reading verbatim transcripts, especially if related to sensitive topics. Some may also have literacy problems or may find it difficult to recall discussions (Hagens et al. 2009). If researchers attempt to reconvene focus groups for member checking, locating participants can be extremely time-consuming and often impossible, therefore the same group composition may not be achievable and group dynamics is unlikely to be replicated. Additionally, due to challenges with recall over time, the outcome and efficacy of member checking being a 'validation process' is questionable (Barbour 2005, Lietz and Zayas 2010).

Taking the above issues into account in addition to the principles of weak social constructionism whereby meaning making is created through multiple realities and that this they can change over time, it was thought that member

checks would serve little purpose in terms of enhancing credibility. Rather, a focus group dissemination session was conducted. This, Barbour (2005) argues is a more useful approach to member checking as it enables researchers to stimulate and embellish further discussion around the preliminary findings and interpretation. As validation of findings is not the aim of the focus group dissemination sessions, these can also be conducted with original participants or with new individuals with similar characteristics.

For this study, as the public and HCPs' focus groups were analysed together, one focus group was convened consisting of three members of the public and two healthcare professionals. Two healthcare professionals were part of one of the original focus groups, and the three members of the public were not. The focus group lasted approximately two hours and consisted of short presentations of each of the final focus group themes followed by in-depth discussion. The session was audio recorded and written consent was given by attendees. Light refreshments were also provided.

The focus group dissemination session enabled further thinking and conceptualisation of the findings which helped inform further interpretation and conclusion drawing. It was not thought to be beneficial or achievable to conduct a focus group with media professionals due to the geographical location of the media professionals. Moreover, the interviews yielded data that was pertinent to each individual's role and responsibility in risk reporting,

rather than gaining an understanding of risk perceptions and responses as with the public and healthcare professionals.

Summary

This research study was developed with the underpinning assumption that perceptions are developed and formed as a result of interaction with others. In doing so the methods were chosen so that rich illuminations of shared construction and meaning could be gleaned. The following three chapters will now present the findings of this study: Chapter Five presents the media coverage analysis; Chapter Six presents the public and healthcare professionals' focus group findings; and Chapter Seven presents the media professional semi-structured interviews. The findings chapters focus only on the findings, leaving the overall interpretation and discussion for Chapter Eight.

Chapter Five: Media representation of a *C.difficile* outbreak

Introduction

To gain a deeper understanding of how *C.difficile* is represented in the media, this chapter presents the findings of the media coverage analysis of a major *C.difficile* outbreak. The findings are presented under the two main themes and various subthemes that were developed as described in the previous chapter (Table 10). This chapter addresses the first research question:

1. How was information about *C.difficile* and associated individuals framed in the newspapers during an outbreak?

Table 10: Media coverage analysis themes and subthemes

Main themes	Sub-themes
<i>Constructing C.difficile</i>	<i>"C.difficile as a war"</i> <i>"C.difficile as a monster"</i>
<i>Constructing identities</i>	<i>"Victims"</i> <i>"Villains"</i> <i>"Heroes"</i>

Constructing C.difficile

C.difficile as a war

With a specific focus on death, the metaphoric descriptions of *C.difficile* as a war signalled the seriousness of the situation. *C.difficile* was often portrayed as the enemy which deliberately caused death. This tone was set on the first day of coverage and was consistently maintained throughout as further deaths continued to occur. Headlines portrayed *C.difficile* as being the “killer”, being “lethal” and “deadly” (Sugden 2008, Daily Mail) and the number of deaths were often referred to as “the tragic toll”. Additionally, the outbreak was portrayed as a “crisis” (Robertson 2008a, Daily Mail) in which it “claimed lives” (Sweeney 2008, The Times) and deaths were reported as “fatalities” (Grant 2008a, The Sun).

The use of this terminology also implied that *C.difficile* was clearly winning ‘the war’ which was further enhanced by frequent reference to patients as ‘victims’ (Williams 2008), thus portraying the idea of victimhood as being powerless against the enemy. Additionally, this evoked an image of a degree of physical punishment towards those affected, thus enabling a strong connection between the enemy (*C.difficile*) and its target (patients). This is exemplified and enhanced by the use of specific metaphoric language and capital letters in the following extract:

“A LETHAL superbug has killed EIGHT pensioners [...] in grip of a deadly C.diff outbreak [...] the tragic toll was uncovered after a recent cluster of three new cases [...]” (McAulay 2008, The Sun).

Reinforcing the significance of this, The Times provided explicit detail of how the hospital in question was initially built in order that victims of a potential nuclear war could be treated. The story told how the hospital had built a *“super-size mortuary to accommodate hundreds of extra bodies”*. The kitchen was also *“three times larger than needed for a hospital of its size to all them to cope with the extra strains of feeding casualties and refugees”*. It went on to report that the partitions that separated the blocks to make them into wards could all be *“quickly knocked down to leave big open spaces where injured people could be brought in and laid on mattresses”*. In addition to this, it stated that medical staff were *“taught how to catch, kill, skin and cook a rabbit so that they could pass on the skill to survivors”* so that they could *“live off the land”*. Staff were also told to *‘keep quiet about what they saw’* (Reid 2008b, The Times).

Not all coverage, however, adopted such a negative war-related tone. Using the same metaphoric approach, an idealistic stance was also portrayed whereby the Scottish Government (namely Nicola Sturgeon, the then Health Secretary and Alex Salmond, the then First Minister of Scotland) were reported to be taking positive action in order to ‘win the war’, thus putting them back in control. Here, the metaphors used imposed a situation of defence and

counterattack, thus reflecting the physical strength of the political power. This was reported as the Scottish Government planning to “*defeat the scourge of hospital-acquired infection*” (Nicolson 2008a, Daily Mail).

C.difficile as a monster

There was frequent use of terms throughout the coverage such as “superbug” (Sweeney 2008, The Times), “*terrifying*”, (McAulay 2008, The Sun) “*horror*”, (Bruce 2008, Daily Mail) “*aggressive*” (Robertson 2008a, Daily Mail) and patients “*succumbed to C.difficile*” (Grant 2008a, The Sun). Such terminology represented *C.difficile* as similar to a destructive monster which had exemplary physical strength. Consequently, it conveyed the illusion that it is was uncontrollable and therefore posed a significant threat to human health.

Such terms were used alongside descriptions of the perceived severity of *C.difficile* and how this deviated from the norm. For example, articles stated that it was “*20 times more toxic than the normal form of illness*” (Nicolson 2008b, Daily Mail) and that “*antiseptic washes used to keep MRSA under control don’t work with C.diff*” (McAulay 2008, The Sun). Additionally, compared to MRSA it was “*three times deadlier*” (McAulay 2008, The Sun) and the number of cases reported were believed to be “*just the tip of the iceberg*” (Bruce 2008, Daily Mail). The emphasis on the potential severity and strength of *C.difficile* also highlighted that it did not only affect the vulnerable patients. For instance:

“Our mum was a hardy woman. She had never been to the doctor in 40 years [...] but it was as soon as she got diagnosed, that her health went on a downward spiral [...] she was struck down by C.diff in the hospital ward and was dead within a week.” (Bruce 2008, Daily Mail).

The use of historical analogies on the first day of reporting enabled journalists to contextualise unfolding events and to illustrate the severity and impact of *C.difficile*. A previous highly publicised outbreak at the Maidstone and Tunbridge Wells NHS Trust in 2007 (Healthcare Commission 2007) where 90 patient deaths were reported was referred to (Reid 2008a, The Times). This perhaps could be seen to be indicating to readers that the current outbreak may be a repetition of the Maidstone and Tunbridge Wells outbreak.

Constructing identities

As described in the previous chapter, clear identifies of victims, villains and heroes associated with the outbreak were created throughout the coverage. However, what was of particular salience was that some of these identifies were not fixed. The following sections illustrate how multiple, and at times contradictory, renditions of specific individuals were evident as the outbreak progressed, situations occurred and new information came to light.

Victims

The construction of the victims and victimhood largely focused on the families affected by the outbreak. The victims were represented as powerless, vulnerable and needed to be protected. This was presented using emotive descriptive references such as “*victims*” (Sweeney 2008, The Times), “*vulnerable*” (Nicolson 2008b, Daily Mail) and “*elderly*” (Reid 2008a, The Times). Stories also reported personal profiles of affected people, providing explicit accounts related to their death, thus encouraging reader visualisation. These mainly took the form of personal testimonies, such as:

“She (mother) went downhill almost overnight. She had been able to talk and recognise everyone and had been getting better. She went from drifting in and out of consciousness and it ended up that she couldn’t even recognise us. I had not seen her for a couple of days before she got C.diff and the difference was huge. She was in pain all the time and had constant diarrhoea. She looked like death warmed up. She had lost a lot of weight, her face was drawn and you could see her bones [...] The whole family is devastated. We are all very close and could not believe my mother had died” (Bruce 2008, Daily Mail).

An additional construct of the victim was a whistle blower at the hospital. Firstly, the whistle blower wished to remain anonymous, thus highlighting their professional vulnerability in terms of being anxious about the consequences of being identified. Secondly, the concept of victimhood in this sense was to

explain that despite voicing concerns to management at the hospital, they failed to provide healthcare workers with adequate facilities to cope with the number of infected patients. Additionally, no specialist support was provided to help them deal with the complex issues they were faced with. Notably, the emotive concepts used for this story may have also encouraged anger towards those responsible for not taking appropriate action, thus enhancing the identities of the villains (Davidson 2008b, *The Times*). This reliance of personal testimonies and emotive representation was evident from both broadsheet and tabloids newspapers, although less so in the regional newspaper.

Villains

There were a number of 'villains' constructed throughout the coverage. These were individuals who were seen to be responsible for the outbreak or for not taking action. They included the Health Board, in particular the Chief Executive of the hospital, the Health Secretary Nicola Sturgeon and doctors and nurses at the hospital. Whilst constructing the identities of the villains, strategies were also adopted to illustrate the conflict that arose between them.

Chief Executive

Right from the beginning of the coverage, the Chief Executive was portrayed as the main villain. This began by Ross Finnie, the Scottish Liberal Democrat leader implying that the Health Board was not telling the truth. As the number of deaths continued to increase, Wendy Alexander, the Scottish Labour leader

also became prominent in the accusations against the Chief Executive indicating that the deaths were being ‘*covered up*’ and that they were not reported to the Health Secretary (Davidson 2008a, The Times). Explicit details were then reported about the specific failings of the Chief Executive, such as inadequate surveillance systems in place, a lack of resources and facilities that were not fit for purpose in the hospital and patient care equipment not being fit for purpose. At this time, in some coverage, as the Scottish Government were reported to be unaware of these issues, they were not portrayed as the villains, but rather as further victims (MacLeod 2008, The Times).

The Chief Executive’s responses to these allegations continued to enhance his profile as the villain as stories presented him as taking little responsibility for the situation. His lack of accountability was further heightened when he denied allegations that staff had been complaining about the conditions at the hospital for several years and attempted to apportion blame onto others:

“No doubt there have been shortcomings and I bitterly regret those. If it turns out there have been fundamental shortcomings which should have been acted on previously that had not been acted on by senior management then, certainly, I will apologise” (Paterson 2008, The Herald).

Controversy continued as explicit details of the Chief Executive's salary and pension package was published as one headline stated:

"SCANDAL OF FAT CAT HOSPITAL BOSSES: As killer bug spreads, grieving hit out over pay rises for top officials" (Grant 2008b, Daily Mail).

Consequently, coverage presented an array of angry responses from individuals such as the daughter of a patient who had died and Margaret Watt, from the Scottish Patient's Association stating his *"patronising impertinence is astonishing"*, it was *"obscene"* and a *"disgrace"* and demanded his resignation (Grant 2008b, Daily Mail).

Government

Following the initial coverage, as more information came to light with regards to potential reasons for the emergence of the outbreak, conflict was reported between opposing political parties. Details of accusations made towards Nicola Sturgeon about not implementing *C.difficile* guidance in Scotland despite it being in place in England was a significant feature. This then saw a change from her being portrayed initial as a victim to one of the villains. Such accusations included being aware of the problems prior to the outbreak, yet not acting upon them and being aware of the new *C.difficile* guidance in England but not implementing it in Scotland (Robertson 2008a, Daily Mail).

Additionally, despite the number of deaths increasing, it was reported that Nicola Sturgeon was reluctant to conduct a public inquiry, instead favouring an official internal inquiry. This generated additional anger by other opposing parties, external stakeholders and families of those who had died. Enhancing this persona of being the villain, especially in earlier coverage, it was the allegations made towards Nicola Sturgeon that journalists focused on most, especially in tabloid newspapers (Bruce 2008, Daily Mail). Minimal coverage was given in terms of her responses. While accusations were directly quoted in lengthy sentences, when Nicola Sturgeon's responses were published, journalists mainly use their own words, rather than her direct quotes. If quotes were used, they tended to print only one or two words, thus appearing not to be providing the whole context. More Government representation was given by broadsheet newspapers than tabloids.

Doctors and nurses

Doctors and nurses were also portrayed as villains in two main ways. Firstly, journalists referred to a previous highly publicised *C.difficile* outbreak possibly in an attempt to draw upon similarities between the two, despite previous outbreaks not being connected to the one being reported:

“After the outbreak in Kent [...] the Healthcare Commission said that an ‘itinerary of errors in infection control had caused the “avoidable tragedy’. It added that nurses at the trust were too rushed to wash their

hands and left patients to lie in their own excrement” (Reid 2008a, The Times).

When providing information about the causes of *C.difficile*, references were made towards doctors’ and nurses’ practice. For example doctors were blamed for the overuse of antibiotics (Nicolson 2008b, Daily Mail). This was further enhanced by reports that “*significant reductions in C.diff*” has occurred elsewhere in the UK following changes by doctors in the way antibiotics are used as it demonstrated that *C.difficile* is preventable (Reid 2008a, The Times). Additionally, doctors and nurses were held responsible for not decontaminating their hands (McAulay 2008, The Sun). This accusation was also reinforced when newspapers reported that a hand hygiene expert had been assigned to ensure that standards were met (Reid 2008a, The Times). One controversial article questioned whether “*lazy healthcare staff*” were actually responsible for the outbreak:

“Could it be the great untouchables of modern life, doctors and nurses are so beyond criticism nobody publicly says they are the real culprits in these appalling bug outbreaks? [...] I think it’s time we were told what’s actually going on in our hospitals and why they have become so unsafe. It would be criminal if it was just down to staff being too lazy to wash” (MacKenna 2008, The Mirror).

Heroes

The heroes within the coverage were illustrated as those exposing and questioning the villains and taking action to deal with the outbreak and stop the spread of infection. They were seen as the protectors.

Government

The key heroes identified within the coverage were politicians, including Nicola Sturgeon, the whistle blower and the journalists themselves. Initial construction of the heroes when the outbreak was first reported were opposing politician leaders, namely LibDem and Labour. These individuals were portrayed as a form of patient advocates in that they were the ones who doubted the Chief Executive's initial explanation that the increase in deaths and numbers of cases was due to better detection methods. Additionally, they provided the first indication that the truth was not being told and implied that things were being "*covered up*" (Nicolson 2008a, Daily Mail). This advocacy strengthened as further deaths were announced, when they exposed Nicola Sturgeon's failure to take action after problems at the hospital prior to the outbreak had become apparent in addition to guidance not being implemented. The Labour Leader was also the first to publically challenge Nicola Sturgeon's initial statements about holding an official inquiry and argued that the inquiry should be a public one, independent of the government.

Paradoxically, while Nicola Sturgeon was frequently portrayed as the villain, this was not the case in all coverage. Davidson (2008a, The Times) wrote a

lengthy article about the deaths being “*hidden from Health Secretary*”, how she had “*uncovered*” the “*tragic toll*” and outlined the action that Nicola Sturgeon was taking to address the problems. Further details of this were published which provided a positive story as to all the action Nicola Sturgeon was taking (Dinwoodie 2008, The Herald). Within these accounts, Nicola Sturgeon talked compassionately about “*our patients*” and being “*determined to ensure lessons are learned*”. Additionally, she was also reported praising the Health Board for the “*concerted drive towards improving hand hygiene at the hospital*” rather than solely criticising them for wrong-doing (Robertson 2008b, The Times). It was also at this time that she changed her view about an official inquiry, stating that she believed the case for an independent inquiry was “*overwhelming*” (MacDermid 2008, The Herald). These articles also did not provide further criticism against Nicola Sturgeon.

Journalists

Although a significant amount of coverage included statements from a number of key individuals directly involved in the outbreak, the journalists themselves, more so in tabloid newspapers, indirectly portrayed themselves as heroes by acting as an authoritative voice for the public. Exclusive to tabloid newspapers, journalists often spoke using the ‘representative we’ in that they assumed the position of the reader and a member of the public. This is illustrated by one journalist when he wrote “*I think it’s time **we** were told what’s actually going on in our hospitals...*” (MacKenna 2008, The Mirror). Similarly,

in another story, a journalist wrote “*last year the Scottish Sun reported how **our** hospitals were in the grip of a deadly C.diff outbreak*” (McAulay 2008, The Sun). Adopting the conversationalist tone as highlighted in the article earlier criticising doctors and nurses, another tabloid newspaper also took this controversial approach, but this time to question the motives of the campaigners who fought to prevent the hospital from closing down:

“But I can’t help thinking about those campaigners who have found to ‘Save the Vale’ [...] I wonder if we’d have seen the tragedies of the past few months if this crumbling old building had been partially closed down? Many campaigners ignore expert advice, preferring sentiment. But at what price?” (McColm 2008, News of the World).

Summary

Throughout the media coverage analysed, *C.difficile* was constructed and represented as a frightening and dangerous infection which appeared for various reasons, to be uncontrollable and unmanageable. However, the way in which key individuals associated with the outbreak were constructed was more complex. There were, at times, contradictory renditions of actors as the media created victims, villains and heroes. Additionally, depending on how the newspaper chose to frame particular parts of their stories, identities changed over time as new events occurred and additional information came to light. This media coverage analysis therefore provides an understanding of the way in which information about a *C.difficile* outbreak was communicated

to the world over a three week period of time. Within the following chapter, ways in which the public and HCPs use the media as a backdrop in which they contextualise risk factors that they associate with *C.difficile* is presented. In doing so, it highlights that the media are an important and influential source of risk information about *C.difficile*.

Chapter Six: Public and healthcare professionals focus group findings

Introduction

This chapter presents the public and healthcare professionals' focus group findings in which risk perceptions and responses in the context of *C.difficile* were explored. It addresses research questions 2 and 3:

2. How and why do the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?
3. Are there similarities and/or differences in the way the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?

Profile of the public and healthcare professionals

Eight public focus groups (four in the West of Scotland and four in the East of Scotland) were undertaken. A total of 39 public participants took part in the study, of whom 20 resided in the West and 19 in the East. Table 11 illustrates characteristics of those public participants.

Table 11: Characteristics of public participants

Group & location	Participants	Age range	Gender	Occupation	Heard of <i>C.difficile</i>	Newspaper reader
1: West	Paula Jenny Helen Audrey Lisa Denise	16-55 years	6 females	Housewife Manager Manager Paralegal Housewife Catering	5 yes 1 no	Local, tabloids & broadsheets
2: West	Betty Jane Lindsay Nancy	46-66+ years	4 females	Retired Retired Housewife Administrator	All yes	Local & broadsheets.
3: West	Sheila Lucy Annie Diane	46-66+ years	4 females	Retired Unemployed Retired Therapist	All yes	Local, tabloids & broadsheets
4: West	Cath Brenda Elaine Gail Pat Connie	36-66+ years	6 females	Retired Service advisor Self employed Teacher Retired Housewife	All yes	Local & regional, tabloids & broadsheets
5: East	Grace Sam Jessica Isobel Kim	16-55 years	5 females	Retail assistant School pupil School pupil Student Student	All yes	Local & regional, tabloids & broadsheets
6: East	Victoria Ruby Molly Bella	46-66+ years	4 females	Retired Retired Retired Housewife	All yes	Local & regional, tabloids & broadsheets
7: East	Max Charlotte Alice Pam Harry Julie	56-66+ years	4 females 2 males	Retired Retired Housewife Retired Retired Retired	5 yes 1 no	Local & regional, tabloids & broadsheets
8: East	Janet Judy Theresa Linda	66+ years	4 females	Retired Retired Retired Retired	All yes	Local & regional, tabloids & broadsheets

Seven HCP focus groups (three in the West of Scotland and four in the East of Scotland) were undertaken. Two of these focus groups consisted of infection prevention and control practitioners (one in each geographical area). A total of 29 HCP participants took part in the study, of whom 12 resided in the West and 17 in the East. Table 12 illustrates characteristics of those HCP participants.

Table 12: Characteristics of healthcare professional participants

Group & location	Participants	Age range	Gender	Length of clinical experience	Designation	Experience of <i>C.difficile</i>	Newspaper reader
9: West	Shirley Sarah Sandy	26-45 years	3 females	26-45 years	All IPCPs*	All yes	Local & regional, tabloids & broadsheets
10: West	Jan Arlene Suzy	26-55 years	3 females	12-31 years	Manager Sister Care assistant	All yes	Local & regional, tabloids & broadsheets One said none
11: West	Sonya Derek Pauline Maire Chloe Megan	16-55 years	5 females 1 male	2-25 years	Staff nurse Dep. manager Housekeeper Care assistant Care assistant Care assistant	5 yes 1 no	Local & regional, tabloids & broadsheets
12: East	Tracy Lily Sharon Mary Adele	26-55 years	6 females	15-36 years	All IPCPs*	All yes	Local & regional, tabloids & broadsheets
13: East	Evonne Jack Beth Heather Kirsty	26-55	3 females	12-31 years	Care assistant Staff nurse Care assistant Care assistant Care assistant	All yes	Local & regional, tabloids & broadsheets
14: East	Maria Jackie Gill Claire	26-55	4 females	7-28 years	Care assistant Staff nurse Care assistant Charge nurse	All yes	Local & regional, broadsheets
15: East	Maggie Louise Betty	36-65	All females	4-34 years	Charge nurse Care assistant Charge nurse	All yes	Local & regional, tabloids & broadsheets

*(IPCPs) Infection Prevention and Control Practitioners

The focus group findings are presented under four main themes and various subthemes that inductively emerged during the analysis as described in Chapter Four (Table 13).

Table 13: Public and healthcare professionals' focus group findings

Main themes	Sub-themes
<i>Being vulnerable</i>	<i>"Consequential fear"</i> <i>"Being in the firing line"</i>
<i>Attribution of responsibility</i>	<i>"Questioning attitudes, knowledge and skills"</i> <i>"Not like the good old days"</i>
<i>Making sense of competence</i>	<i>"Doing the right thing"</i> <i>"Being reassured"</i>
<i>Evaluations of the communicators</i>	<i>"The media: the bleak, the bad and the miserable?"</i> <i>"The experts: to trust or not to trust?"</i>

Being Vulnerable

The main theme 'being vulnerable' evolved from the concept of 'susceptibility', identified in the risk perception literature. It is claimed that if a person believes he or she is particularly susceptible to a health-related risk, it will likely heighten risk perceptions and encourage them to take precautionary measures (Bond and Nolan 2011). However, it quickly became apparent during the focus group discussion and the subsequent analysis that participants did not refer to themselves as being particularly susceptible to acquiring *C.difficile*. Rather, their vulnerability manifested itself in a wider

sense in terms of concerns around issues that they associated with *C.difficile* and the perceived negative outcomes that could arise. Sadness, upset, fear and at times anger was often aroused as they recalled and shared stories of direct and indirect experiences, and also about what they had learned from others. This often demonstrated the level of vulnerability they felt in terms of almost reaching a point of approaching hopelessness.

Although both the public and HCPs were similar in terms of their awareness of their own, and other people's vulnerability, there were differences in terms of context. On the one hand, the public mainly spoke about personal vulnerability in terms of their own health and well-being, and that of their friends and family members. Healthcare professionals on the other hand, were more vocal about their professional vulnerability, in particular how they believed they are perceived by others.

“Consequential fear”

This subtheme encompassed the level of vulnerability participants felt in terms of the perceived potential negative consequences of being in hospital, or as a result of the actions taken by others or by themselves. Such discussions were notable in all focus groups and were, at times, quite emotive. In order to make sense of their fear or concerns, participants drew upon many direct experiences as well as situations they had learned about from friends, family, colleagues and through media coverage.

The public often delineated their fear through detailed descriptive stories using colourful metaphors which seemed to encourage others within the group to create a sense of visualisation as to how bad things were. The sharing of personal experiences tended to be more evident among those living in the outbreak area. However, even with the absence of direct experience, those in the non-outbreak areas drew more upon what they had heard from others or what they had read in the newspapers. The following excerpt was from a public focus group in the non-outbreak area illustrating fear around the lack of cleanliness, which they collectively associated with the spread of *C.difficile*:

Emma: *"You said you thought C.difficile was commonly found in hospitals?"* (Researcher)

Grace: *"Yeah, the hygiene problem, that's quite a worry."* (PB5-21)

Emma: *"What aspects of hygiene do you think are poor?"* (Researcher)

Kim: *"Lack of equipment, lack of training, lack of chemicals, lack of staff."* (PB5-25)

Grace: *"I think what concerns me is that when you read the media, is that there is an awful lot of cleaning done by contracts. So they are employing people to come in who don't necessarily well... they'll obviously get training but they've no.... Like there's nobody actually on*

the ward saying “that isn’t properly cleaned” or “you’re not working through the hospital regulations, through the proper cleaning procedures”. Now, through the media, you do hear all about these people have gone in to see their parents or whoever and they are horrified at the standard of cleanliness and they have actually had to clean themselves.” (PB5-21)

Emma: *“Have you heard of people doing that?” (Researcher)*

Grace: *“Only through the media. I mean it shouldn’t happen.” (PB5-21)*

What is noteworthy, later on in this focus group conversation, all participants criticised the media for sensationalist and inaccurate reporting, especially tabloid newspapers. However, in the above conversation, they appeared to have accepted the information they gained from the media.

This level of public vulnerability, in terms of being fearful was also recognised and frequently acknowledged by most HCPs, and was also largely accounted for by perceived negative and unwelcomed media coverage. Indeed one HCP stated that she believed that if it were not for the media, then *C.difficile* would not cross the minds of patients or the public. Others agreed:

Kirsty: *“I think the media creates fear in patients who come into hospital, you know, they’ve got this great fear.” (HCPB13-61)*

Heather: “*Everything’s negative that goes in the paper and the stuff that gets said about it, it’s all bad.*” (HCPB13-60)

Evonne: “*I think they [the public] think it’s [C.difficile] a really bad thing.*” (HCPB13-57)

Jack: “*Yeah.*” (HCPB13-57)

Kirsty: “*If they get it, they’re going to die.*” (HCPB13-61)

Evonne: “*Yeah, they’ll die.*” (HCPB13-57)

Kirsty: “*Because of what they read, cos that’s what you read.*” (HCPB13-61)

Much of the public’s belief was that *C.difficile* was fundamentally associated with poor cleanliness. In order to rationalise these beliefs, they spoke of past direct or indirect experiences as hospital patients and/or visitors. For example some stated that they had observed seeing blood stained sheets, toilets contaminated with urine and faeces, dusty lockers and dirty bed tables. Additionally, hospitals were criticised for no longer having that “*hospital smell*”. As a result, many felt intrinsically dirty while being in a hospital, either as a patient or just visiting, to the extent that they said they were often frightened

to touch anything when in hospital. What was also of relevance in one public focus group, was that poor standards of cleanliness seemed to only be associated with hospital settings. Some noted that despite care homes housing elderly and nurse-dependent people, they always found them to be clean, tidy and “*smell free*”. Participants stated that they were therefore unable to comprehend why hospitals could not achieve this level of cleanliness also. As a result of this, participants frequently told of specific actions they took to protect themselves and their families from infection. These included taking a variety of cleaning materials into hospital and cleaning toilet and bed areas themselves, refusing to go to particular hospitals for treatment and taking out private healthcare so that they could avoid certain hospitals.

Shared stories and experiences of poor hygiene and cleanliness were very much influenced by affective imagery using perceptual representations. In this sense, in addition to the imagery symbolising a simple visually-based mental representation it also attached negative and emotional connotations. This was demonstrated by participants’ verbal and non-verbal signs of disgust, such as raised tones of “*ew*” and “*yuck*” and screwing up their noses, gasping and covering open mouths. As further stories were shared, voices were raised and high pitched, people talked at the same time, often over each other, they interrupted each other and completed each other’s sentences. Such storytelling seemed to function as an invitation for others to join in to continue in the creation of images of ‘terribleness’ to the extent that sometimes it almost seemed like a contest of who had the worst story to tell. This sharing of, and

building upon each other's experiences reinforced the act of the co-construction of meaning. More broadly, such rapid and emotive co-construction of meaning seemed to influence associations of risks which appeared to be much wider rather than directly linked to *C.difficile*. The following conversation demonstrates public participants' experiences which are not directly related to *C.difficile*, but were used in order to make sense of their perceptions of poor care and cleanliness which they used to associate with *C.difficile*:

Helen: *"My sister was in for an operation on her bowel and her bladder in [hospital name] and she was lying basically in blood and she asked to get cleaned and it took them hours [...] That place, you could stir it with a stick."* (PA1-1)

Lisa: *"I was in [hospital name], and this is rather horrible, but I was in [hospital name] and OH MY GOD!"* [Researcher's emphasis] (PA1-5)

Denise: [interrupts] *"Toilets. Don't even speak to me about it."* [holds her hands up high and looks up to the ceiling] (PA1-6)

All: [everyone talking over each other loudly. Researcher intervened]

Lisa: [interrupts] *"I was totally and utterly stressed out the whole time I was there. I wasnae ready to be sent home. I had just had a heart attack and wasnae ready to be sent home. Nowhere near it."* (PA1-5)

Denise: *“I bet you didnae want to stay there.”* (PA1-6)

Lisa: *“No, they were like that “we’re gonna have to send you home cos you’re making yourself ill”. Just being in there, it was HORRENDOUS! [Researcher’s emphasis]”* (PA1-5)

Jenny: *“I’ve heard the toilets in [hospital name] are like the toilets at a festival”* (PA12).

All: [screws up their noses, covers their mouths and makes loud “ew” noises. Lots of laughter]

Using the state of festival toilets as an example to describe the condition of hospital toilets was a clever strategy from Jenny. As all participants within the group were young (<36 years old), it is likely that they would have similar perceptions of how bad toilet festivals are, therefore this comparison enabled a shared understanding of the standard of perceived cleanliness in this particular hospital. It is noteworthy the reaction of loud laughter when Jenny talks about the toilets being like festival toilets. While the image of this in relation to a hospital is shocking, the laughter in this situation may signify the perceptions of shock in the realisation that this could actually be true, rather than it being perceived as funny in the traditional sense. What was also notable about such negative experiences being shared was that they were all

readily accepted as told, with no-one questioning or challenging any of the details. Within this group, this may be because hearing about negative experiences from others provided some degree of validation for their own experiences or perceptions.

It was also evident that for some public participants, a poor standard of cleanliness was frequently associated with poor nursing care. This understanding seemed to be based on the assumption that if healthcare workers, particularly nurses, did not pay attention to cleanliness then it was unlikely that they would pay much attention to the quality of care they provided. Despite the admission of having little technical knowledge and understanding of *C.difficile*, most public participants correctly recognised a number of the risks in relation to HCP practices which can contribute to the spread of *C.difficile*, such as poor hand hygiene and the inadequate use of personal protective equipment. Again, these perceptions were often rationalised by previous experiences and observations, what they had heard from other people and from what they had read in the media.

What was noteworthy, however, was that despite them stating they firmly believed poor infection prevention and control practice would likely increase the risk of the spread of *C.difficile*, few public participants stated they have challenged staff about this in the past. Additionally, most stated they probably would not in the future. When probed further about this, there appeared to be an innate fear of the potential consequences of speaking up or challenging

staff. Grace and Isobel, from the non-outbreak area were talking about their beliefs that poor hand hygiene practice could contribute to the spread of *C.difficile*. They then reflected on the poor practice they had observed while their very poorly mothers were in hospital. Although they accept this practice could put them at risk of *C.difficile*, they rationalised why they would not challenge staff:

Emma: *"What about staff practice, did they decontaminate their hands?"* (Researcher)

Grace: *"Not really."* (PB5-21)

Isobel: *"Some I did see wash their hands yeah, but you are only there for an hour at visiting times."* (PB5-24)

Emma: *"Would you challenge a member of staff if they didn't [wash their hands]?"* (Researcher)

Isobel: *"No."* (PB5-24)

Grace: *"No. They might take it out on the patient you know."* (PB5-21)

Isobel: *"Yeah, that's what I mean."* (PB5-24)

Grace: *“I would be worried about her [mum], but I wouldn’t say anything.”* (PB5-21)

Isobel: *“You’d be abandoned in your bed for hours!”* (PB5-24)

These perceptions were substantiated by experiences of those who stated they had challenged HCPs for poor infection prevention and control practice in the past. A number of participants stated that as a result of doing so, they observed a negative change in staff attitude towards them for the rest of the time they were in hospital because they were viewed as a *“trouble maker”*. Notably, participants who reported to have challenged staff in the past about poor practice tended to be of a younger age whereas those who stated they were less likely to challenge staff tended to be older participants.

For HCPs, consequential fear dominated many of the discussions in both geographical areas, but in a different context to the public. Although HCPs felt vulnerable to being potentially exposed to negative outcomes that they associated with *C.difficile*, it was not in relation to ill-health. Rather it was a fear of the impact on of their professional actions, particularly around the consequences of their communication with patients and their families. One example of this was during a conversation among HCPs in a community hospital in the outbreak area about an elderly gentleman with *C.difficile* who had been transferred to them from an acute hospital. Despite having a significant number of years’ experience within healthcare, two young care

assistants stated that they made a concerted effort *not* to talk to the gentleman's family about anything related to *C.difficile*. Rather, they would ensure that communication about this would always occur with a senior nurse. It could be assumed that a reason for this may be a lack of technical knowledge of *C.difficile* on their part. However, they explained that this particular family were "*very difficult to manage*" owing to them being angry about poor nursing care the gentleman had received at the hospital from where he had been transferred. Thus, they were more fearful of the family's reactions towards them.

A similar type of consequential fear was also echoed by HCPs in different focus groups, particularly if a patient had acquired *C.difficile* while in their care. They stated that as a result they were frequently faced with upset relatives seeking answers to some particularly difficult questions that they often felt uncomfortable about answering. In the following excerpt, some infection prevention practitioners offered an explanation as to why nurses are fearful about this:

Shirley: *"I think they're [nurses] scared about telling them [patient relatives] the wrong information really. I think that's the problem. They fear that they are not gonna give them the right information and then that's when they come back and bite them."* (HCPA9-40)

Sarah: *“Or lead them down a path. Patients often ask “well where did I get this from?” Well not so much patients, but their family. Patients generally are accepting, but their family – “why have they got that?” “why did you just notice it now?” So I think they are afraid of how much they give away. It’s fine telling them about an organism, but when you start talking about spread, that leads to the open questions about “so where have we got this from?” “Is the hospital clean?” (HCPA9-41).*

Shirley: *“I think as well, the patient groups that we tend to deal with are isolated. They’ve kinda been here for quite a long time cos of underlying problems before and the family can be then quite aggressive “well they’ve been here all this time, so why is this happening now?” (HCPA9-40).*

Even if HCPs do know the answers to questions asked by families, some HCPs explained that in an attempt to protect themselves from negative consequences after a patient has acquired *C.difficile*, such as encountering patients and relatives’ anger, they may purposely censor information. For example, they would not always disclose all possible reasons as to why the patient acquired *C.difficile*, especially if it may have been associated with poor infection prevention and control practice.

What was observed was that during these discussions, the HCPs did not acknowledge that the reason they are scrutinised by patients and relatives is

because, while in their care, the patient has acquired a potentially preventable healthcare associated infection which can cause serious illness. Only one HCP, a staff nurse from the non-outbreak area, considered the situation from the relative's perspective. She stated that if it was her mum in hospital and she had heard "something about that ward" in relation to *C.difficile*, she would want to know everything about the ward in order to be reassured that her mum was safe and would therefore ask a lot of questions.

"Being in the firing line"

This subtheme stemmed from discussions around the perceived long term impact of patients acquiring *C.difficile*, and *C.difficile* outbreaks. Participants believe as a consequence of such events occurring, they are now seen as some sort of villain who causes healthcare-related harm. Moreover, they believe this has resulted in them constantly "*being in the firing line*" and that they seem to have no control over it. Notably, this was not only from an individual/professional perspective, but also from a community perspective.

From an individual/professional perspective, almost all HCPs were very vocal about how they thought they were perceived by others and how vulnerable this made them feel. Most believed that they worked in a blame culture whereby they were constantly "*under a microscope*" as everything they did was scrutinised by the public, other healthcare professionals, the Government, friends, family and especially the media. An agreement shared by many was a belief that they were often "*in the firing line*" due to other people's lack of

understanding of their role and little appreciation of the challenges they faced in clinical practice. For example, one focus group pointed out that their ward failed their hand hygiene audit and were reprobated for it, yet this had been the result of doctors' bad practice rather than that of the nurses. Additionally, some stated that patients can have impossible expectations in terms of keeping them infection free when they often do not take appropriate actions themselves such as good hygiene practice. Others also stated that they are expected to ensure high standards of infection prevention and control practices are maintained, yet staff shortages often prevents this from occurring. As a result, patients can become infected with *C.difficile*.

The emotional impact of feeling like they were constantly "*in the firing line*" was evident among many HCPs. They stated that they felt unappreciated and devalued which had significantly impacted on their overall morale and job satisfaction and therefore affected their job performance. The strength of this vulnerability was often demonstrated by the way in which specific issues were discussed. For example, participants' mood quickly changed from being loud and chatty to quiet and subdued, and they often simply stared down at the floor or at others as they sought endorsement of their perspectives:

Jan: *"I've been a nurse for a long, long time and people... there is a blame culture and nurses don't have the same respect. People used to have a.... what's the word I'm looking for? Aye, probably respect is the right word. You were admired if people knew you were, you know,*

a caring person. Now the minute something goes wrong they are jumping on your back." (HCPA10-43)

All: [Nods of agreement]

Arlene: *"It is... its quite demoralising. It is in general."* [Stares down at the floor] (HCPA10-44)

[Long silence]

There was a strong, unified agreement across all HCP focus groups that one of the main reasons for constantly being "*in the firing line*" was negative media coverage. They believed they were "*sitting targets*" and that the media appeared to literally wait for them to do "*something really bad*" so they could "*get them*", with one HCP stating that they are just ready to "*go in for the kill*". Such perceptions seemed to evoke feelings of frustration, upset and at times anger. This emotional response was particularly noteworthy from HCPs in the outbreak area as they recalled the vast amount of negative media coverage about the *C.difficile* outbreak that had occurred.

However, the general consensus across both geographical areas was that the media deliberately manipulate coverage about *C.difficile* by only reporting certain parts of a story in order to magnify wrong doing and portray HCPs in a bad light. For example, they felt that when reporting *C.difficile* cases

journalists do not segregate the number of patients that acquire the infection in the ward and those that were admitted who already have *C.difficile*. Therefore, the situation that is reported looks worse than it really is.

Many also believed that because *C.difficile* transmission is often linked to poor practice and poor levels of cleanliness, this increases media interest in it because it is connected with controversy and blame, of which HCPs believe they are the focus. In order to make sense of these perceptions and account for them, an array of media stories were drawn upon. One story in particular upset a number of participants within the outbreak area because of the consequence it had on the hospital staff:

Chloe: *“It’s the press. The papers.”* (HCPA11-49)

Pauline: *“Lorraine Kelly. She turned round and said “the domestic’s used the same mop all over the hospital”. I’ve never seen that happen. Now what happened after she said that... that’s when all the domestics from the [hospital name] – they were getting spat on and everything in the street by the public. The girls had a really hard time. Dirty hospital.”* (HCPA11-48)

Everyone: [gasps]

Chloe: *“It’s always negative isn’t it? Obviously there’s not very much good about it but it’s always just the bad press you read.”* (HCPA11-49)

Sonya: *“It’s always seen as being the staff’s fault in how it’s spread. It’s always being put across as being the staff’s fault and that’s maybe not always the case.”* (HCPA11-46)

This sense of protectiveness towards cleaning staff by HCPs appeared to be intensified by how the public within that community reacted towards the cleaning staff after the above story appeared in the newspapers. In the above excerpt, Pauline is a housekeeper in a care home and was also a domestic supervisor in another healthcare setting, which could explain her protectiveness over cleaning staff.

In addition to being perceived as being *“in the firing line”* as a professional individual, this level of vulnerability was also evident from a community perspective. Many public and HCP participants in the outbreak area believed that as a consequence of the outbreak, their community and local hospital had been irreversibly stigmatised. This stigmatisation, they felt, was significantly exacerbated by the negative media coverage surrounding it.

From an additional community perspective, many public participants from the outbreak area also described their angst about a merger of two Health Boards which had occurred a few years previously, and how there had been a steady

closure of wards and departments at their local hospital since. As a result of this, they believed that little effort was being made by senior management to ensure high standards of cleanliness and care. They also perceived the closing down of services as a deliberate and calculated “attack” on and “invasion” of their local hospital by the health board, the Government and even the media with little consideration for the voices of the local community. Moreover, they believed that ‘cut backs’ of wards and staff numbers from their local hospital, enforced by the merger were fundamental to the occurrence of *C.difficile* and the outbreak, evoking feelings of frustration, anger and distrust:

Lisa: *“Mainly for me it’s been what’s being in the newspapers but I don’t believe a bloody word of any of it, cos it’s all hyped up to shut the [hospital name].”* (PW1-5)

Paula: *“That’s true.”* (PA1-1)

Helen: *“The Government have got to stand up and say “We’re at fault here” cos they’re the ones that are coming with these cut backs.”* (PA1-3)

Emma: *“So you think cut backs are an issue?”* (Researcher)

Denise: *“Oh aye, they’re shutting wards.”* (PA1-6)

Helen: *"I mean everything is dealt with at [hospital name] now."* (PA1-3)

Jenny: *"I think to be honest, with [hospital name], if it hadn't been for this whole C.difficile thing, it would have been something else to run with because they are just closing it down ward by ward and um..."*
(PA1-2)

Denise: [interrupts] *"Service by service."* (PA1-6)

Jenny: *"They are trying to cover up by doing up the wards and making people think they are not closing them, but then they close them down."*
(PA1-2)

Such strong beliefs regarding their local hospital and healthcare services *"being in the firing line"* were compounded by a sense of community vulnerability for most participants in the outbreak area. What is important is that this vulnerability was not determined by the occurrence of the *C.difficile* outbreak as one would perhaps expect. Rather, despite extensive campaigning and petitioning, it seemed more about what had been imposed on the community (closing down of the local hospital wards and services). As a result, this uncontrollable situation was perceived as a significant negative outcome of the outbreak. Indeed, at times, there was a sense that the initial risk of *C.difficile* actually became irrelevant and in its place was that this

imposition had invariably created inequitable exposure to perceived additional risks. For example, closing of services meant people had to travel great distances for certain healthcare services to another hospital where they felt they were exposed to poor healthcare practice and substandard care. Thus, these shared anxieties served to contribute to the co-creation of additional risks related to this situation over which participants felt they had no control.

There was however, an exception to this community vulnerability and protectiveness towards the local hospital. Participants in one public focus group in the outbreak area were actually very critical of the local hospital and shared with each other experiences of poor care, and poor attitudes by nurses and doctors in order to rationalise their views. As a result, they stated that they would do everything they could to avoid going there for future healthcare. Notably, this particular group in comparison to the others, had only lived in the area for relatively short period of time, thus possibly providing an explanation for the lesser 'attachment' to it than the others.

Attribution of responsibility

Both the public and HCPs across both geographical areas appeared to be very certain about what and who they believed contributed to the acquisition of *C.difficile* and the occurrence of a *C.difficile* outbreak. Narratives connected to this theme were often emotive, fast and loud and required little probing, illustrating the strength of feeling about these issues. Views were often

rationalised through sharing of personal experiences, experiences of others, or referring to what they had read in the newspapers. While attributing responsibility, it was also noted that it provided a platform for participants to reinforce their own competence. In doing so, it then enabled them to distance themselves from the 'irresponsible'.

“Questioning attitudes, knowledge, skills and behaviour”

Knowledge, attitudes, skills and behaviour of others were frequently called into question. This was not only from an individual level but also at a group and organisational level. The Government were highly criticised by the public participants particularly so from the non-outbreak area, for continually enforcing the reduction of healthcare staff. Additionally, some felt that the Government spend too much money employing managers “*on huge salaries*”, which they believed resulted in further healthcare staff cutbacks. This apportion of blame enabled many to make sense of and rationalise why healthcare staff sometimes had no choice but to take shortcuts and were not able to adhere to policy requirements all of the time. As a result, it seemed to serve as justification as to why *C.difficile* infection outbreaks occurred.

One particular aspect that most public participants believed the Government responsible for, in both geographical areas was in relation to a perceived reduction in the standard of cleaning services within hospitals. They appeared to be certain that was directly associated with the occurrence of *C.difficile* infections and outbreaks. Many accused the Government of abolishing in-

house cleaning staff, and therefore were responsible for healthcare organisations having to use external cleaning contracts. Although it did not seem clear as to why the public believed this to be the case, one participant from the non-outbreak area stated that she had read about this in the newspapers. For many, perceptions of external cleaners were that they were not part of the healthcare team, they are paid very low wages and they are not supervised. As a result participants stated that they believed that the cleaners did not care about ensuring high standards of cleanliness, rather they simply wanted to do their job as quickly as possible. Some participants stated that they believed the use of contract cleaners, in comparison to in-house cleaners which were used years ago was one of the reasons why *C.difficile* has transpired in recent years.

Healthcare managers were also highly criticised by the public participants from both geographical area. Collectively, most saw healthcare managers as being merely “*pen pushers*” sitting in their “*ivory towers*”. Similarly, HCPs stated that they believed healthcare managers to have inadequate skills or knowledge and “*no idea of what is happening at ward level*”. The consequence of this they stated was that managers were not thought to be able to perform their job effectively and run a healthcare organisation appropriately. This was believed to be a significant contributing factor to *C.difficile* outbreaks. Additionally, a general consensus was that managers simply allowed staff to “*do as they pleased*” without enforcing policy or good practice. For example, a frequent topic of conversation by the majority of the public was their concern about the

risk of the spread of infection due to nurses being outside the healthcare setting still wearing their uniforms, and by smoking at hospital entrances. Unexpectedly however, it was not nurses who were directly criticised for this, rather it was viewed as the fault of the managers for allowing this to happen. Therefore it was those who were in a position of authority who were being questioned.

Perhaps surprisingly, not many HCPs were critical of managers. Only one HCP focus group in the non-outbreak area shared the public's view of managers and stated that "*these people who are at the top of the shop*" are so removed from what happens on the wards or how hard it is for the nurses. These same participants also voiced their frustration with regards to being the people who speak to the media when there are *C.difficile* outbreaks, because they believed they have little understanding of what was going on, and therefore do not provide the correct information.

Nurses, however, were not exempt from criticisms around lack of competence. Notably, criticisms about nurses were directed towards qualified nurses rather than ward assistants or nursing auxiliaries, especially by the public from the outbreak area. Many of these discussions initially began around how the lack of competence of nurses contributed to the occurrence of *C.difficile*. However, discussions did at times evolve and broader experiences of nursing care were drawn upon. Although some of these experiences did not appear to be directly associated with *C.difficile*, they seemed to be used in order to rationalise or

make sense of risks that the public associated with *C.difficile*. While nurses did not seem to be held responsible for their actions in terms of not following certain policies as highlighted above, they were heavily criticised for other aspects of their practice.

Participants drew upon a range of personal experiences, and experiences they had heard from other people, such as nurses showing little care or attention towards patient needs, not being visible on the wards to enforce good practice among visitors, and for not being available to talk to patient family members. One participant stated that when she visited her mother in hospital, she observed “*an awful high turnover of staff*” which led to “*a lot of different layers of care and not a lot of information provided*”. Others commented that nurses seemed to want to only “*do the basics*” but with little attention to the things that are important to patients, such as assisting with basic hygiene. Nurses were also perceived as being more concerned with “*sitting in the back room having coffee together*” or “*gathered around the nurses’ station talking about whether to have a Chinese or Indian for their supper*”. As a result, participants stated that with this lack of care and compassion, they were not surprised that *C.difficile* outbreaks continued to occur:

Connie: “*Well that particular time as well, the following day I went up and it was... there was like three beds, a two and a one and a wash hand basin. Cos, to me the [hospital name] is like a maze when you go in to the actual wards. And he [her dad] was in the bed there [pointing]*”

and there was a man here [pointing], and that bed was empty. There was a wash hand basin that had a leak. Now there was a bag of something, I don't know whether it was clean washing or fresh linen or whatever. It was in a big, big orange bag. And this water was actually crossing the floor. So I went along and I saw this nurse and I said "excuse me, I said there's a leak in that wash hand basin and the water's running down the floor". In the next ward, the glass partition, the man was actually dying and his family were round his bed. She said "I'll go and get somebody", she said "I'm just going off shift" and she just walked away and left me. Do you remember that Pat?" (PA4-20)

Pat: *"Oh, aye." (PA4-19)*

Connie: *"I was horrified." (PA4-20)*

Emma: *"Where do you think that attitude comes from?" (Researcher)*

Elaine: *"No matrons." (PA4-17)*

Connie: *"I think because, sorry, just to finish Elaine. I think that some nurses that work in hospital, maybe I am being a bit cruel, and I don't know. I think they are brain washed into thinking they are so overworked that they think well..." (PA4-20)*

Pat: "Aye." (PA4-19)

Brenda: *"I'm no doin another thing..."* (PA4-16)

Connie: *"They just think "I'm overworked and I don't have time for this". Would you walk away and leave somebody for 5 minutes? I mean personally I would have went and got a mop and a bucket and done it."*
(PA4-20)

Brenda: *"But that is society, as I said, once again remember when I had my toe done? The two of them had been done and I was so ill with one of them and all they [nurses] kept saying was "we told you it would be painful". No, I said "there's something no right", but the nurses were going off shift. What they were doing was they said "just leave it for the night shift to do" cos they.. it was as if they've got to do something right. So they made me wait til the night shift came on, they took the bandage off, and what they had done was when they operate on your toe, they put a band on your toe, but as they started to cut it, they started to wrap the bandage round so in effect the band hadn't been cut off. So my toe was nearly black and they had me laying waiting all day [the nurses on the previous shift], mind?"* (PA4-16)

Pat: "Aye." (PA4-19)

Brenda: *“The night shift had come in cos they had done their quota for the day [day nurses]. Sometimes it is like the “poor me” syndrome. But do you know something? Everybody’s job’s got a “poor me”. I’ve got a job and I finish at 8 o’clock, but if I’m speaking to someone, I cannae turn round and say to them, “by the way, I’m finished now, it’s 8 o’clock, so you’ll have to hang up and phone someone else”. I cannae do that, you’ve got to keep going. Sometimes it’s twenty past eight, half past eight by the time I get out, but you cannae just go “oh, that’s it, my time is up”. But I think that’s what it is – it’s the “poor me” syndrome as well.”*
(PA4-16)

In addition to criticisms towards nurses, there was also a collective sense of agreement throughout all public discussions in both geographical areas that doctors have bad attitudes towards other HCPs. They believed that doctors think they are more important than others and therefore feel they are exempt from specific healthcare duties:

Lisa: *“I was in the high dependency ward not that long ago [...], but they lassies [domestic staff] were coming in to clean the ward and they could hardly clean them for all the doctors standing about talking. So half the ward wasnae getting cleaned. And the amount of doctors that came in and out of my ward to treat myself and other patients and DIDN’T wash their hands. It was shocking!”* (PA1-5)

Denise: *“That was my main concern... as some of the doctors and things like that, they were not changing gloves.”* (PA1-6)

Lisa: *“Cos I actually had a conversation with an auxiliary when I was in a heart ward and she was saying “how am I supposed to get this cleaned?” and there were six or seven doctors all standing at reception and she couldn’t get anywhere near the rooms for them just standing there talking.”* (PA1-5)

Denise: *“It’s hard when they just come in and you are just kinda pushed out of the way.”* (PA1-6)

Jenny: *“Maybe they felt they were above having to do that, when really everyone has to.”* (PA1-2)

The above dialogue also demonstrates how participants often questioned the competence of specific HCPs who were seen to be in a position of authority, in this case doctors. Consequently, the actions or inactions of these authoritative HCPs were thought to have a negative impact on other HCPs who were perceived as having little or no authority. The above excerpt illustrates this in terms of how Lisa, Denise and Jenny made sense of the perceived poor level of cleanliness. Rather than holding those who cleaned the wards responsible for this, collectively, they shifted the responsibility onto another group of HCPs who are generally highly ranked in the hierarchy of the

healthcare profession yet are not perceived to have a direct role of cleaning wards. It is noteworthy that once a collective agreement had been ascertained, such discussions then appeared to encourage participants to continue to elaborate about further competence issues as was seen above.

Additionally, Denise's comment about domestics being "*kinda pushed out of the way*" and Jenny's comment about doctors thinking they were above having a cleanliness responsibility seemed to portray the doctors as being arrogant and antagonists. It is also noteworthy that Denise used to be a hospital domestic and she also knew Lisa on a social basis, therefore they were more likely to be able to relate to these challenges thus strengthening empathy towards the domestics.

A further observation of such a conversation is that assumptions were often made about particular situations, yet did not always appear to be based on in-depth knowledge and understanding of roles, responsibilities and factual information of what was going on. For example, as a patient, it is unlikely that Lisa would be aware of the reasons why the doctors were standing around talking. Although, it could be that a ward round was occurring, the implication within this dialogue was that it appeared to be more of a social gathering. Lisa's perceptions of this visual situation therefore appeared to generate a shared construction of meaning within the focus group without knowing the true context.

With regards to HCPs perceptions of competence towards other nurses, they seemed to be far more reserved than the public in that they did not hold nurses personally accountable for inappropriate practice. HCPs from the non-outbreak area stated that while they realised *C.difficile* incidences and outbreaks often occurred due to errors in practice, they believed it was the bigger acute hospital environment that was of more significance. Many stated that the high levels of activity and patient turnover, lack of resources and lack of time contributed to nurses having “*less time to care*”. Further explanations were also offered:

Gill: *“Do you think we are just luckier being in a smaller hospital? And you know, having a smaller turnover of staff? Things don’t get missed the same you know. When you get a hand over, you get a proper hand over that kind of thing. Whereas, I think in the bigger hospital, there’s such a turnover of staff and you know, I’ve had both my parents in and you phone up there and they [nurses] don’t even know who they are [patients]. And that puts you off at the phone call. You think ‘well you don’t even know who they are and it’s your ward!’”* (HCPA14-64)

Maria: *“And they might not even be in that ward – sometimes they get moved from ward to ward”* (HCPA14-62)

Gill: *“I know, I’m not blaming it, because I know it’s fast and furious in these bigger hospitals and maybe things are missed but I think because*

we are smaller, things are passed on so then things aren't missed so easily. I think that's why it (C.difficile) broke out somewhere a bit bigger"
(HCPA14-64)

Maria: *"We've got more time to care don't we?"* (HCPA14-62)

Although the public spoke more freely about questioning competence of HCPs, many did not seem to acknowledge that they also had an important role in the prevention of infection of *C.difficile*. Rather, they appeared to be completely reliant on HCPs to do this for them. Discussions from the majority of HCPs confirmed that from experience, they believed this was the case. Many stated that they found it very problematic and challenging for them and they felt infection prevention needed to be a team effort in which patients and the public are an important part. Nearly all HCPs stated that they did not think the public had an adequate level of knowledge and understanding of *C.difficile*. This they stated, was a major barrier for the adoption of correct preventative measures. Other HCPs also stated that they believed the public did not want to gain any knowledge and understanding. As a result, many HCPs felt that if and when someone acquires an infection or an outbreak occurs, this allows the public to automatically hold the healthcare staff responsible for spreading the infection, when perhaps this could have been to the result of patient non-compliance with preventative measures. Many HCPs stated that this caused them a great deal of frustration because education of patients and families was an important part of their role. One HCP stated:

Claire: *“Yeah, but you can guarantee that if you put one [patient information leaflet] down for a patient’s relative or you give them it, you can guarantee it’s still on the patient’s locker a day later. They haven’t taken it away and you think ‘well have you read it while you’ve been in’ you know? They haven’t you know, they haven’t because it’s still very often sitting on the patients locker”* (HCPA14-65)

Only one HCP (from the non-outbreak area) stated that she thought the public wanted more information, stating *“they are hungry for it”*, but believed this was perhaps only in small community hospitals/healthcare settings as the bigger, acute hospitals are too big to ensure patients and public are educated appropriately.

“Not like the old days”

Both the public and HCPs, frequently reflected upon and looked favourably on the *“good old days”* and easily recalled vivid stories of personal experiences from many years previously in order to support their perceptions of how things were not as good today. Many also frequently remarked that they believe *C.difficile* had only come to the fore in recent years which was rationalised by stating that it was unheard of years ago. A number of reasons were offered as to why they thought this way. They believed this to be because many standards within healthcare had slipped due to poor leadership and management styles and bad decision making processes. They also believed that there had been fundamental changes in how people respond to authority

within healthcare. For example, older public participants, some of whom were retired healthcare workers, often described the strict regimental-like and autocratic styles of leadership and management when they were employed. There was also a clear sense of fear towards these authoritative individuals. However, rather than viewing this type of authority or leadership in a negative light, they talked about it positively and with great fondness and discussed the impact that this had on people's behaviour:

Annie: *"I can recall, I mean I started at the hospital in the 1960s and I can recall back then when we used Glutaraldehyde to clean the wards [laughs] then we went through all the health and safety things when they withdrew that because it was unsafe, but I think... We worked in the [hospital name] and it was a really good hospital and really, really clean. We had excellent... we had a doctor [name], and before her was it [name] before her, can't remember her name, she was in microbiology. They were in charge of hospital infections and they were really on the ball. Really strict. All the nurses were well taught how to deal with the cleaning and the cleaners were all taught about hospital infection. It's a case of authority as well cos if a sister asked you to do something you would do it."* (PA3-13)

Lucy: *"Exactly."* (PA3-12)

Annie: *"You don't just ignore what she was saying."* (PA3-13)

Sheila: *"If you were going to be an inpatient or outpatient in hospital, you would usually get an information pack of your treatment or whatever."* (PA3-11)

Diane: *"You see situations where people go into the ward to visit and they actually get onto the bed with them and they lie upon the bed."* (PA3-14)

Sheila: *"That's something that just used to not be permitted. They were never allowed to sit on the bed."* (PA3-11)

Lucy: *"That's another thing... I knew there was something else. In the old days... we sound like a bunch of old fogies don't we?!"* [Laughs] (PA3-12)

[All laugh]

Annie: *"Things were much stricter. Nurses had to change in their outdoor gear in hospital."* (PA3-13)

Diane: [interrupts] *"That's right."* (PA3-14)

Annie: *"Everything was sent away to the laundry and was properly laundered and came back. I remember. Remember Miss X?"* (PW3-13)

Lucy: *“Oh, flip yeah!”* [Raises hands in the air and laughs] (PA3-12)

Annie: *“She got somebody out in uniform and saw them on the street and they were called up and they were disciplined for being out. Nowadays, they take their uniforms home. You see them out on the street with their uniforms on.”* (PA3-13)

These experiences and views are clearly very different to participants' views of today's leadership as discussed previously whereby the perception is that there is no real leadership to ensure that policies and procedures are adhered to adequately, or to reprimand those who do not adhere to policy.

The above dialogue is also a good example of interaction characterised by consensus and how this impacted on content. The adjacency pairs exchanged between Annie and Lucy illustrated experience sharing facilitated by a joint acceptance of obedience to authority *“in the old days”* in comparison to today by the explicit recognition of specific people and situations. Such shared understanding was evident by raised voices, animated interaction, use of hand gestures and smiling and laughing as they often finished each other's sentences. This highlights the importance of homogeneity both in relation to the interaction between them, and how this can impact on others around them in terms of gaining endorsement of their perceptions. Although Sheila and Diane were friends of Annie and Lucy, they did not have this shared experience of healthcare. Such intimate connection between the two could

have inadvertently risked the exclusion of Sheila or Diane from the conversation. However, this was not the case as both Sheila and Diane joined in with ease and helped build a co-construction of meaning. The shared evidence that Annie and Lucy therefore used to articulate their viewpoints was substantial enough to gain whole group agreement. As a result no-one changed their minds, questioned each other or offered alternative views, thus a wider and fuller picture was co-created.

Healthcare professionals also talked about the 'old days', but to a lesser extent than the public and not quite as directly. However, it was still evident at times. When discussing the level of knowledge and skills nurses had for managing *C.difficile* and dealing with patients and families in relation to *C.difficile*, there was mutual agreement that many nurses did not. Additionally, some felt they did not have the compassion and caring nature to be able to care appropriately for patients with *C.difficile*. This perceived incompetence was also offered as an explanation as to the negative way in which they believed nurses are perceived by the public and the media. One HCP stated that this was why the media have reported on a number of occasions that nurses are "*too posh to wash*". Some HCPs were clear in that one of the reasons for this today's style of university training in comparison to the 'old style' way in which many of them had been trained:

Jan: *"I don't think they're [nurses] good at that any more [communicating with patients]. I don't know if that's the University based*

training and they don't have that patient contact. Arlene and I are both old style training and I think you develop your bedside manner the more you are on the wards and working with the ward team with the patients, they don't. They don't even go in and work anymore "I'm just here to observe" kind of idea, then 3 years later they've gained a degree or diploma. They are it and do they really know what they are talking about. Aye, it's scary. I wouldn't like to be a patient now with some of them looking after me." (HCPA10-43)

Arlene: *"Why do you need to learn academic to be a nurse? You don't. Doctors are there, doctors diagnose, doctors prescribe. That's not why nurses became nurses. That's not why I became a nurse. I became a nurse for hands on looking after patients. They've lost that contact and I think that's why families don't respect you anymore – cos they see you sitting writing a care plan [...] They're not interested in anyone's family are coming in, nurses aren't out working with the residents anymore."* (HCPA10-44)

Suzy: *"It just all lands on us. D'you know what I mean? We're carrying everyone."* (HCPA10-45)

Arlene: *"That's how they're developing things. They're all round a computer or something. You get signs in hospitals now you know – staff are not available at visiting times to speak to relative cos they're doing*

a hand over. Quarter past seven and there's no-one available? Oh god, I'm late, I better get out quick". I couldn't believe that when I saw that!"
(HCPA10-44)

Jan: *"Those nurses aren't nurses anymore."* (HCPA10-43)

This perception was also shared by a number of other HCPs who stated that they believed some students nurses did not actually want to be nurses as they used to in the 'old days'. Rather it was an easy way to gain a degree and diploma. Although such discussions at times, seemed to be more from a general perspective rather than directly related to *C.difficile*, an important point noted by some HCPs was that this lack of competence put other members of the nursing team under pressure to compensate for this, which is when the risk of adverse events such as the acquisition of *C.difficile* can occur.

Making sense of competence

Both the public and HCPs had clear views of what they thought was good practice in relation to preventing, managing and controlling *C.difficile*. This theme links closely to the 'attribution of responsibility' theme. While participants were vocal in apportioning responsibility and blame, it inherently afforded opportunities to make explicit efforts to defend their own position in terms of acting in the correct way, and that regardless of any situation, they

did not deviate from this. In doing so, most participants were keen to present themselves as being competent.

“Doing the right thing”

Frequently and consistently throughout all focus groups, conversations around being competent were largely dominated by participants’ perceptions of their *own* competence rather than the competence of others. Despite the admission by some, particularly the public, that they did not know much about what *C.difficile* was, what the symptoms were and how it could be treated, they seemed keen to convey that this did not have a negative impact on how they behaved. By using an array of personal experiences, they interjected discussions in order to explain how they always adhered to good practice and that their behaviour was not recognised as anything other than the correct practice. In order to help further enhance their level of competence, their experiences of good practice were often told within the context of bad practice by others, or unacceptable situations that they had observed. For example, the importance of hand hygiene was discussed frequently by the public participants in relation to preventing *C.difficile* and as general good hygiene practice. Additionally, in order to protect themselves from *C.difficile* and other healthcare associated infections, such as MRSA, they recognised that cleaning their hands on entering a hospital ward at any time was important. However, many expressed their concern that through experience of visiting hospitals, they would often find that there were no alcohol hand rubs at the

entrance of hospital wards. Some also found that if hand rubs were present, the containers were often empty, dirty, or they were not clearly visible.

What was also of significance for many public participants was the belief that there was a lack of commitment by staff to promote good hand hygiene among visitors, in particular nurses. For example, many stated that they felt disappointed that nurses do not appear to encourage visitors to clean their hands, reprimand those who do not, reinforce the importance of hand hygiene or show people the correct way to clean their hands. They believed that if nurses did more to encourage infection prevention and control such as hand hygiene, then visitors would have better adherence and the risk of *C.difficile* would be reduced significantly. During these discussions, many public participants were keen to segregate themselves from these types of people and ensure it was known that they *always* cleaned their hands on entering hospital wards, regardless of the situation. They further explained that even when there were no facilities visible, they would *always* seek them out by asking a member of staff or going to find a sink rather than not clean their hands. Additionally, a number of participants were also keen to point out how diligent they were about ensuring that their children cleaned their hands when in hospital despite frequently observing other parents not doing this:

Lisa: *“Whenever I go in, I always clean my hands, I always do cos I’ve been in there [hospital name] umpteen times, but having said that,*

mainly adults I've seen doing it [cleaning hands] with the exception of doctors. But I don't see anyone making their children do it." (PA1-5)

Paula: *"See, I make my child do it when I go in."* (PA1-1)

Lisa: *"Really? I've never seen anyone making their child do it and let's face it, children have their fingers up their noses."* (PA1-5)

Paula: *"My sister was up in the [hospital name] and we were going in and I was right.... But he automatically goes, and he's only five. He automatically... he goes and does it himself [cleans hands]."* (PA1-1)

When the public participants were asked whether or not they take any additional precautions to protect themselves from *C.difficile*, many stated they did and were keen to share their actions with each other. Although the question put to them was about protection against *C.difficile*, their responses suggested that these were standard actions they took when going in hospital in relation to general hygiene rather than responding specifically to the risk of *C.difficile*. Examples of such behaviour included taking in packets of wipes or disinfectant sprays to clean around their hospital bed and table, pressing hospital lift buttons with keys and opening doors with their elbows. Within the group, these actions were not seen as extraordinary; rather they were simply seen as examples of good, responsible actions. Others' did however describe the more extreme measures they took:

Bella: *"And your own general hygiene comes into it I think. I mean when I go into hospital, I've got my wipes and my own gels and stuff."*
(PB6-29)

Emma: *"That was my other question actually. Do you do any more when you go into hospital? So you've got your wipes Bella?"*
(Researcher)

Bella: *"Yeah!"* (PB6-29)

Ruby: *"Bottle of Dettol."* (PB6-27)

Emma: *"Bottle of Dettol? Do you really?! What do you do with it?!"*
(Researcher)

Ruby: *"Wipe the toilet seat!"* (PB6-27)

Emma: *"Do you really?"* (Researcher)

Bella: [nods in agreement] *"As I say, I buy these little throw away gloves, and I put them on when I go to the toilet and I take my wipes, and I'll do the seat and I'll do the handles with a different wipe before I'll use the toilet."* (PB6-29)

Emma: “*So that’s telling me perhaps you are concerned when you go into hospital about C.difficile or picking something up?*” (Researcher)

Bella: “*But then, it hard not to*” (PB6-29)

The above dialogue is of particular interest in relation to behavioural influences as it suggests that due to the extreme measures they go to keep themselves protected, Ruby and Bella are fearful of infection. However, in an earlier conversation they stated that *C.difficile* would not cross their minds if they were admitted to hospital in the future. Additionally, as previous patients, they described mainly positive experiences of healthcare they had received, and praised the hospital for high levels of cleanliness. Molly on the other hand, who was another participant in this focus group, stated that she *would* be concerned about *C.difficile* and because of this, she would not want to go into hospital unless it was absolutely necessary. Unlike Ruby and Bella, Molly did not share any experiences (good or bad) of being a patient. However, as a retired community nurse, Molly did share with the group on a number of occasions, her concerns around poor cleanliness and poor infection prevention standards in addition to her perceptions about the lack of “*rules*” regarding infection prevention. As these issues were highlighted frequently by Molly as well as the acknowledgement of her being a retired nurse, this may have influenced Bella’s change of view about being concerned about infection. Moreover, it may have encouraged both Bella and Ruby to ‘join rank’ with Molly and share their accounts about using extreme cleanliness measures.

What was also noticeable that while Molly used her own previous experience of good hygiene and good practice to compare to the perceived poor standards she was referring to, she did not give examples of experiences to support her current perceptions of poor standards. What she did do however, at different periods during the discussion, was to point out newspaper stories about poor practice she had read. Although she believed that newspapers stories about *C.difficile* scaremonger the public, her perceptions of poor standards may have subconsciously been influenced by what she has read in the newspapers.

For HCPs, “*doing the right thing*” was frequently discussed mainly in relation to their own professional practice, often as an attempt to justify their position within their profession. Similar to the public they also used their examples of good practice alongside experiences of bad practice by others in order to present themselves as competent practitioners who always adhered to policy. Those working in more rural or community healthcare settings praised themselves for not having many incidences of *C.difficile* in their environment. This, they proffered was due to them working well as a team to ensure infection prevention and control practice within their ward or area was of a very high standard. Moreover, when they did have a patient with *C.difficile*, most were quick to state that this was usually to the result of the patients being transferred to them with the infection from another healthcare setting, rather than it being acquired in their area. Yet, even though they did not have much experience caring for and managing patients with *C.difficile*, they drew upon specific challenging situations in order to highlight their competence. The following

exemplar illustrates the impact of having a *C.difficile* patient being transferred to a care home from a hospital and how they worked together as a team, despite having little help from others out with their ward to ensure that the patient was cared for appropriately:

Derek: *"I've dealt with C.diff. The wee fella at the end of the corridor there. He was transferred here from [hospital name] and when he arrived, he was a very ill man. It was not ideal transferring someone with C.diff but he was here because there was problems with the Health Board so he was moved here and that was the first time I've dealt with it, um... Certainly, when he arrived it was the first time we ever really had to sit down and read policies. Policies are meant to be put in folders and ignored as everybody knows, but whenever he came here, it was the first time we actually sat down and think, read the policy and go through everything - who do I contact, and go through everything else. And that wasnae because of the media thing, that was not in the media, um, even though he was part of an outbreak. But suddenly it was on your doorstep and it was quite serious. [...] See, whenever he came in, I always say... we do have an infection control team but, no, WE took the responsibility, WE did things, WE got the policy oot er, and I was contacting people, um, but was there somebody overseeing us, saying this is what you do to go from a to b to c? No. There wasnae a problem patient coming in and someone coming in saying I'll work here for a couple of days to take you through this. No. It was er, you were notified*

that there was a situation, do a wee bit o digging and deal with it."

(HW11-47)

Megan: *"We did get training on it though."* (HCPA11-51)

Derek: *"Uh-huh."* (HCPA 11-47)

Megan: *"They'd come in and explain everything that we had to do in the room and we minimised the staff that went in and everything - 2 staff. We delegated floors in the morning and 2 members of staff on that floor were told that you have to deal with that man all day which reduced the risk as well."* (HCPA -51)

Derek: *"But they were an employer of [name], there wasnae any outside agency coming in. Um, we had no real information from the Health Board where he came from. He just had a kinda standard transfer letter that told you that he was on x medicine and that was pretty much all. If he didn't have a family with him, we wouldna have had any information. It was the fact that we knew he was coming and that we've got our own infection control team and did it ourselves. Whereas I would have thought that before he came, someone fae the NHS who was dealing with him would have came and kinda, you know, led for a smoother transition."* (HW11-47)

Derek largely dominated this conversation and although his claims were not really challenged, Megan, a care assistant, attempted to convey that they did have some help from the 'outside' to ensure staff were competent in managing this patient. However, Derek was eager to dismiss the worth of this contribution and turned the conversation back to their competence. This was not challenged any further. Derek's unchallenged accounts could indicate agreement among others. However, as Derek was the deputy manager, it could also suggest unwillingness by others to challenge someone in a position of seniority. Nevertheless, it is clear that there were slightly different perceptions of a situation that they had both experienced.

Another strategy adopted by Derek during this conversation and on a number of other occasions was to reinforce the high level of competence he and the ward staff demonstrated, in terms of having the ability of putting other people's wrongs, right. In doing so, many HCPs were eager to portray themselves as being more knowledgeable or more competent than other HCPs. Notably however, during the above conversation and similar conversations by other HCPs, they were not specific in terms of who they deemed as less competent, only that they were other ward level HCPs working in other hospitals or healthcare settings. Additionally, during conversations of promoting self-competence, virtually no HCP acknowledged that improvements could be made to their own practice. Only one HCP, an infection prevention specialist practitioner indicated that perhaps there was room for improvement:

Mary: *"Oh yes. We need to be slicker with information. If it's something a bit different or a different unit, we need to be quicker, slicker, find sensitive ways of being more upfront and honest. We need to spend time, and if some of us has to do that, explaining, especially in some areas, the difficulties, because I think sometimes the ward staff do it really well and sometimes it's a complete disaster."* (HCPB12-55)

Adele: *"uh-huh."* (HCPB12-56)

Mary: *"I mean in my career, I've usually been brought in when it's been a complete disaster and it's me that's scraping the relatives off the ceiling and really taking it back to the basics and explaining to them the what and why and how and then they go 'if only I had understood that' and it's those things that don't get done."* (HCPB12-55)

However, by using "we" and "I", the above excerpt shows that Mary seemed to separate herself from those who she felt needed to do better by emphasising her own competence. In Mary's first quote, note how she begins by referring to "we", yet it becomes evident that she does not perceive herself to be in that "we" group as she clearly identifies that she thinks it is the "ward staff" that need to be better at providing information, rather than referring to herself or the team. Her next passage further amplifies where she positions herself in the realms of competence by using elaborate metaphors such as *"it's me that's scraping the relatives off the ceiling"*. Throughout this focus

group discussion, Mary frequently talked about certain things in clinical practice that had gone wrong, or should not have occurred due to other HCPs actions or non-actions, but within a context that demonstrated her competence in terms of “sorting out” what had gone wrong. As a result, there was a sense that Mary felt the need to continually justify her professional worth.

“Being reassured”

Overall, conversations about negative aspects of healthcare which were deemed to contribute to the acquisition and spread of *C.difficile* were more dominant than conversations about positive aspects. However, it is important to note that there were a number of factors that both the public and HCPs drew upon which provided them with reassurance of safety within healthcare. This differed from evaluations of competence in the sense that being reassured was not necessarily about their own practice or somebody else’s specific practice. Often such conversations about being reassured were triggered from the sharing of personal experiences and perspectives

Not surprisingly, for the public, being reassured about a safe healthcare environment and being protected from *C.difficile* was frequently associated with cleanliness, hygiene and the visualness of professionalism. A number of participants highlighted how they felt reassured by “*that hospital smell*” and that they knew when someone had been visiting a hospital because “*you could smell it off them*”. This was also an observation made in a HCP focus group, although it was in the context that they were saddened that the clean hospital

smell did not seem to exist anymore. Indeed, that hospital smell was often associated with perceptions of good care and an enjoyable experience of healthcare in general.

Many public participants stated they felt reassured by the more specialist areas within acute hospitals and also the smaller rural healthcare establishments. This was also commented on by some HCPs, particularly in the non-outbreak area. Participants were under the impression that staffing levels in the specialist areas and rural healthcare settings were higher, which enabled more thorough cleaning and more time to care. Other public participants also believed that specialist wards were happier environments than the general wards. Although being happy was not directly attributed to not being at risk of *C.difficile*, it was still associated with a pleasant and risk-free environment. Additionally, it was believed that because of the above factors, communication between HCPs within these areas was perceived to be better and that “*things didn’t get missed*”. Using their own experiences, Kim, Grace and Isobel talked about perceived differences within healthcare settings and their views on why this may be the case:

Kim: “*I think they [hospitals] are really hampered by the lack of staff. I think they are really under pressure. Individual people are probably good, but they are just under pressure.*” (PB5-25)

Isobel: “Yeah, [hospital name] is brilliant. Have you had your mum in there [asking Grace]?” (PB5-24)

Grace: “No.” (PB5-21)

Isobel: “I had my dad there. It’s fantastic. It’s so nice, every one of them. Really clean, just totally different. They had more time for people and I think that helps. That’s the way all hospitals should be like.” (PB5-24)

Emma: “So the difference between that and a big acute hospital, do you all feel the same?” (Researcher)

Kim: “Um, [hospital name] is OK in parts. I can only go on my own experience. The cardiac care was beautiful. You know that was really nice, but when you are out on the ordinary ward, it’s terrible, I mean, she was allowed to fall and everything. There was just no people there to look after her.” (PB5-25)

Again, although this conversation does not seem to be directly in the context of *C.difficile*, it began by Kim offering potential reasons for *C.difficile* occurring. As the conversation progressed to a more general perspective, it demonstrated the important wider issues or experiences that people may draw upon to make judgements about something.

A few public participants commented on the importance of visibility of staff as this provided them with a sense of reassurance of good practice and care. For example, when they saw domestic staff on the wards, they felt reassured that the environment was being cleaned adequately and therefore, reassured that they were protected from *C.difficile*. Additionally, a few public participants spoke about being in hospital as a patient or as a visitor, and felt reassured by seeing nurses in and around the ward and among patients. The visibility of nursing staff on the wards was often associated with perceptions of being caring and compassionate which, in turn, seemed to provide reassurance that their clinical practice was also of a high standard. One particular public participant spoke of having acquired *C.difficile* on three separate occasions while in hospital, yet she was not angry or frightened and that she trusted the healthcare staff because they were “*lovely*” to her. As a result, she felt that they had provided good care. Additionally, when nurses were visible to patients and visitors, participants felt reassured by the fact that they were able observe their practice:

Linda: *“Well when I was in, well nearly a year ago, just as a day case and where I was sitting, I could watch everything that was going on [laughs] and I did and I would say that the hygiene was very good. [..] yes, the nurses cleaned their hands in between patients and put on gloves, every time.”* (PE8-39)

Emma: *“So you noticed that?”* (Researcher)

Linda: *"Oh yes, and the rubber gloves."* (PE8-39)

Emma: *"So when you see practice like that, it reassures you?"*
(Researcher)

Linda: *"Oh yes!"* (PE8-39)

Janet: *"Yes, yes".* (PE8-36)

Judy: *"You're not frightened."* (PE8-37)

Linda: *"Well you don't feel there's any chance of cross infection that way."* (PE8-39)

Another important indicator of being reassured of good healthcare and safety for many public participants was perceptions of professionalism, particularly around the professional appearance of HCPs. This visualness of professionalism seemed to be associated with having authority and leadership, which provided participants with reassurance that they were competent in what they were doing. This was further substantiated by the association of unprofessional appearance with poor care:

Janet: *"My grandson, last year, after a bit of a car accident, developed pains in his chest and he was put... the NHS said 'oh take him in to casualty' or whatever they call it these days. This was up in Inverness, and um, he was pleased to be seen because we were very worried about him, but the duty doctor came in and he was unkempt, he had shorts on, he had walking boots and hairy socks [laughs] and my daughter was there thinking... I mean, Brian is 21 now, but my daughter was there with him, and she was like 'no wonder there's infections!' I mean, they were so pleased to have a doctor see him and he was fine, it was just muscle strain or something.. but the state of this doctor... OK it was out of hours but there was no excuse for that..." (PB8-36)*

Emma: *"Would it give much confidence?" (Researcher)*

Janet: *"Oh, no. Really, it wasn't at all professional and as my daughter was saying 'so much for infection' you know, his outdoor gear and where's the white coats you know?" (PB8-36)*

Theresa: *"Why don't they wear white coats now?" (PB8-38)*

Judy: *"Are they not allowed anymore?" (PB8:37)*

Theresa: *"Cos that would, you know, for cross infection." (PB8-38)*

Emma: “*Why do you think they don't? Do you have any views on that?*”

(Researcher)

Judy: “*I think now, they have this more casual approach you know, which is fine, it's friendly, but... not so scary as a white coat coming towards you, but...*” (PB8:37)

Theresa: [interrupts] “*But then white coats gives reassurance.*” (PB8-38)

Linda: “*They have authority.*” (PB8-39)

It is pertinent to note that Janet, Theresa and Linda are all 66 years or above, therefore are from a generation that experienced a more authoritative healthcare system and having less autonomy over their healthcare compared with patients today. Thus, they often had no option but to trust HCPs to take care of them and manage risks appropriately. Doctors were also held in very high regard by the older public participants and so the look of professionalism was important. Their white coats were particularly seen to be indicative of someone who has clinical credibility, is professional, knowledgeable and has expertise. While there is no substantial epidemiological link between a white coat and the acquisition of *C.difficile*, Janet's comment suggests perceptions of the white coat imply clean and infection free. On the other hand, failing to wear them may induce evaluations of scruffiness, lack of competence and lack

of hygiene. Although in this dialogue Judy attempted to defend the more casual approach by suggesting that the white coats were scary, this wasn't endorsed by others and Judy did not continue in her defence. In fact, a little later in the conversation Judy stated that she would prefer doctors to be in white coats.

In terms of being reassured, it was the infection prevention and control practitioners from both geographical areas this was mostly pertinent to. They initially looked beyond the local or organisation level and focused on developments that were occurring on a national level to address the burden of *C.difficile*. They reflected on previous years, comparing it to recent times and stated that they felt reassured that the Government was committed to making a concerted effort to reduce *C.difficile*. For example, they described some important national initiatives and innovations that were in place such as new tools, policies and targets. They were pleased to see HCPs at ward and department level engaging in the implementation of such initiatives. Additionally, they stated that despite the *C.difficile* outbreaks that have occurred in the UK, and particularly Scotland over recent years, they believed that "*there is more to learn*". Such progress clearly provided a sense of reassurance that things were being taken seriously and progress was being made at a national level in relation to dealing with and managing *C.difficile*:

Mary: "*I mean, having been around for so very long, um, one of my first outbreaks in 1985 was a C.diff outbreak in [hospital name] in female*

trauma, but after that was over, there wasn't a lot of it. It was very sporadic. So in my 26 year experience in infection control, C.diff was quite slow to get off the ground and be recognised. The testing has changed a lot so the results are different now. We used to have to wait for culture, now we get toxin. So things have changed. The identification of it has changed which means that we have more opportunities to do something about it earlier than you did in the past. So, I think things have changed quite a lot and as Adele said, you know, two or three years ago, there was such a lot of interest and high profile because of [hospital name]. But because of the SAPG [Scottish Antimicrobial Prescribing Group], because of the antimicrobial pharmacists, because of the stewardship, because of the control and because of the improving in the environmental situation, the whole country is now seeing it coming down.” (HCPB12-55)

Adele and Sharon also illustrated how such national progress regarding *C.difficile* has impacted on local level:

Adele: *“I think it's getting better, hopefully from National figures it's getting better and we see it locally, um, we don't have so many cases of C.diff that we did have but we sometimes get blips in certain areas and I think now, I mean Sharon is really honing down and doing some really good work in ward x where you're looking at systems where the staff are really now focusing on antibiotics and they're highlighting*

patients that could be potential C.diff patients as well. So there's a whole different system which I was really impressed they're putting in there and that's still at the start because I don't think we've had any of the patients yet, but I think we're seeing real changes and changes in the staff - ownership of patients with C.diff as well. I think it's been getting better.” (HCPB12-56)

Sharon: *“Yeah, in that particular ward, they're actually training the nurses on antimicrobial prescribing and giving them medication sessions and there's pharmacists involved as well so it's good to see pharmacists being a part of this so it's not just a disease team or infection control. The pharmacists have got a large part to play in it as well.” (HCPB12-54)*

Adele: *“I think it depends on the area but we have lots of areas where, again, I think most of our C.diff cases have been in the medical directorate and I think there is more engagement there with the clinicians and we've been doing more sort of um, case reviews which the nurse managers have been asking for and so the infection control team have been looking at more medical notes than we've probably done before. We're doing it in more detail and feeding that back and having a discussion with the medical staff. Again, if we have cases where it fits the criteria for the Trigger Tools or for a severe case, then the medical staff have been quite um, I suppose amenable to carry that*

out. We had an example of that last week where we've gone and said carry this out, help them and they've wanted to meet up about it so it's been so we're finding it, well I'm finding it better than we did years ago."
(HCPB12-56)

Despite acknowledgement of recent *C.difficile* outbreaks, the infection prevention and control specialist practitioners believe that lessons were being learned, and measures were being implemented to ensure and enhance patient safety as highlighted above. The development of specialist teams such as antimicrobial stewardship also provided reassurance that there was targeted action was being taken and that HCPs, particularly doctors, were engaging with such action. These perspectives however, were offered only from the specialist practitioners. This was not surprising considering they are likely to have more knowledge of national and local policy and initiatives than those working at ward level.

Although these specialist practitioners were reassured that the burden of *C.difficile* was being taken seriously and these initiatives were making a difference, not all HCPs felt the same. One exception was three HCPs in a focus group in the non-outbreak area whereby they stated they thought *C.difficile* has been "*blown out of proportion*" and said they held the media responsible for this. Notably, these HCPs had stated that they have never had a problem with *C.difficile* in their clinical area and any cases that they did get, were usually inherited from another hospital.

Evaluations of the communicators

Both the public and HCPs spontaneously and consistently drew upon two main sources they considered to be important risk communicators within the realms of *C.difficile*: the media and health ‘experts’. Conversations about the media were frequent in all focus groups and mainly focused around newspapers. These conversations were at times loud and emotive as participants had very strong views about them.

Health experts were viewed as individuals or organisations that should have high levels of knowledge about *C.difficile* and, therefore, their role is to disseminate accurate information to others in appropriate ways. There was an overall agreement throughout all focus groups that effective communication from these sources was a crucial part in helping people understand about *C.difficile*.

Throughout discussions about risk communication by the media and experts, most participants voiced their concerns that information and communication about *C.difficile* was lacking. Many stated that, at times, information provided by the media was contradictory and confusing. The public participants openly admitted that they were confused as to various technical aspects about *C.difficile*, such as what it is, how it differs from other healthcare associated infections such as MRSA, how it spreads and how it is treated. Healthcare professional participants also stated that although they realised the public were not knowledgeable about *C.difficile*, they were very fearful of it. For this,

they blamed the media. While the public participants believe that the media did sensationalise *C.difficile* coverage and therefore they stated they do not have much trust for the information they received from the media. Equally, they also expressed their distrust at times of information they receive from expert sources.

“The media: the bleak, the bad and the miserable?”

All participants drew upon media coverage of *C.difficile* and healthcare risk-related stories spontaneously, and without being prompted by the researcher. Moreover, perceptions of the role of the media, in particular newspapers featured very early on in focus group discussions, demonstrating its importance and significance in relation to perceptions. At times, participants had particularly strong opinions about the role of the media and were always keen to share these opinions with the rest of the focus group participants. Similarities were quite consistent among all participants (both the public and HCPs) with very few disagreements or contrasting views being offered. Consequently, discussions often resulted in raised voices, participants talking over one another, finishing each other's sentences and nods of agreement as they were all keen to share their perceptions, observations and experiences.

The overall consensus by both the public and HCP participants was that they believed newspaper journalists sensationalise and dramatise *C.difficile* coverage in order “*whip up interest*” simply so that they can sell more newspapers. As such, newspaper representation of *C.difficile* was often

referred to as being inaccurate, exaggerated and/or untrue. Most participants made it clear, often from the outset of discussions that that they did not believe what they read in the newspapers or that they took stories with “*a pinch of salt*”.

Notably, most public and HCP participants recorded that they read a variety of newspapers (local, regional and national). Most also stated that newspapers were actually their main source of information about *C.difficile*. Nevertheless, many participants, particularly older ones, disclosed their general distrust of journalists, especially those who worked for tabloid newspapers. Broadsheet newspapers were considered to be more credible among older participants and for the younger participants, local newspapers were preferred.

Participants in the outbreak area were more critical of all newspaper coverage, regardless of the type of newspapers. This criticism appeared to be magnified by what they perceived to be untrue representation of the *C.difficile* outbreak that had occurred in their area. A small number of HCPs in the outbreak area stated that they refused to read newspapers because they did not believe what is written most of the time. One of these participants, a young care assistant, stated that by not reading newspapers, the negative stories did not affect her. Consequently, she stated that this made it easier for her not to engage in discussions with friends, family and colleagues about things that were reported in the newspapers.

Despite such claims of distrust and disbelief of newspaper coverage, some dialogue particularly between the public participants indicated that media coverage was accepted more readily than they admitted. The following excerpts taken from one public focus group demonstrates how the media seemed to inform what they thought about newspaper coverage of *C.difficile*. Notably, at the beginning of this focus group these public participants began by stating that newspapers were their main source of information about *C.difficile*:

Theresa: *"I've read about it."* [Laughs] (PB8-38)

Judy: *"I've certainly read about it."* (PB8-37)

Janet: *"Oh yes!"* [Raised tone] (PB8-36)

Judy: *"Cos there's quite a lot in the newspapers when there is an outbreak going on."* (PB8-37)

Janet: *"Yes."* (PB8-36)

Emma: *"So you've read about the outbreaks?"* (Researcher)

All: *"Yes."*

Emma: *“And what’s your impression from what you have read?”*

(Researcher)

Theresa: *“Well, it’s lack of cleanliness.”* (PB8-38)

Linda: *“Sometimes they seem to take a long time to isolate the infected patients from the other ones you know, cross infection.”* (PB8-39)

Theresa: *“Maybe not informing their relatives sooner, you know warning them how serious it can be.”* (PB8-38)

Judy: *“It’s certainly highly contagious.”* (PB8-37)

Theresa was the first to state that she had read about it and her laugh at the end of her admission goes some way to inform the rest of the group that although she had read about it, she did not take it seriously. This could be a tactic to protect her from perhaps being viewed as naive for believing what she had read. However, when the others also admitted to reading about the outbreaks in newspapers, it seemed to provide an overall acceptance of these media stories and therefore encouraged a co-creation of the issues that have been reported thus stimulating further dialogue about *C.difficile*.

Yet, in a turn of events a little later on in this focus group discussion, when the conversation spontaneously returned back to media representation, they were asked by the researcher if they believed what they read:

Janet: “No!” [Laughs] (PB8-36)

Judy: “*I take it with a pinch of salt.*” [Laughs] (PB8-37)

Theresa: “*The Courier* [regional newspaper], *we always think tells it upfront, more than the tabloids.*” (PB8-38)

Judy: “*Yeah, they [tabloids] are more... what would you say.... dramatic.*” (PB8-37)

Emma: “*So you don’t tend to believe what the tabloids say?*”
(Researcher)

Theresa: “*Not all of the time, no.*” (PB8-38)

Judy: “No!” (PB8-37)

Conversely, even further on in the discussion, after talking about a particular *C.difficile* outbreak they had read about in the media, the following dialogue occurred:

Emma: “So you said you read about an outbreak at [hospital name] through the newspapers? What was your impression of what you read?”
(Researcher)

Janet: “Well it was a relatively new hospital so I was quite amazed.”
(PB8-36)

Judy: “Shocked.” (PB8-37)

All: “Yeah.”

Emma: “Did you believe what was reported?” (Researcher)

Judy: “Well you do really.” (PB8-37)

Janet: “Yeah, and it’s a new hospital so...” (PB8-36)

Linda: “And because it is not in this area, you don’t know much about it so you do believe what you read.” (PB8-39)

This example illustrates the complexities of audience responses to media representation. As observed in other focus groups, the degree of knowledge or experience that someone has on a particular situation seems to impact on

the extent to which a newspaper story is accepted and/or believed. For example, because the participants in the above example have little knowledge or understanding of the outbreak that they were referring to, as they did not reside in that area or have any connections to the area, media coverage was likely to be their main and perhaps only source of information.

Similar contradictory discussions were also observed in a number of other public focus groups. However, there was a notable observation about the type of stories that tended to be endorsed. Some agreed that they did believe personal testimonies (i.e. stories that were ‘told’ by people affected rather than reported by journalists). A point strongly emphasised by one participant was that the people telling their story “*have no reason to lie*”. It was therefore not surprising that when trying to contextualise something or make sense of something, for example about poor healthcare practice or poor standards of cleanliness, many participants recalled emotive personal testimonies they had read in newspapers. Additionally, these testimonies were also used to support participants’ views and evaluations of poor staff practice and attitudes.

Healthcare professionals also took a similar stance to the public in relation to their perceptions of media coverage of *C.difficile* and wider healthcare issues believing journalists only want to investigate bad news and in doing so they blow everything out of proportion, twist the facts, only tell part of the story to mislead people, and in doing so they “*discredit clinical healthcare professionals*”. They also tended to be more critical of national newspapers,

in particular tabloid newspapers rather than local newspapers. However, when they spoke about the media, mainly newspaper coverage, they appeared to be more emotive, and at times, visibly frustrated than the public participants. This they stated, was due to the belief that journalists were only interested in the “*the bleak, the bad and the miserable*” such as outbreaks and wrong-doing of HCPs, especially when deaths had occurred. They blamed the media for always reporting negative healthcare stories, adverse events and portraying HCPs, especially nurses, in a bad light. As a result, they felt that the media are specifically responsible for the negative perceptions they believe the public have of them. Moreover, the majority of HCPs stated that they believe newspaper coverage is responsible for public and patient fear of hospitals and encourages them to believe there is likelihood that if they acquire *C.difficile* they will die. One particular focus group did not even believe that *C.difficile* outbreaks should be made newsworthy:

Evonne: *“I don’t see why it’s of any interest to the general public. Say we had an outbreak here of it [C.difficile]. Why is it of any interest to anyone else that there’s an outbreak here?”* (HB13-57)

Jack: *“Just the people that are here.”* (HB13-58)

Evonne: *“You know, the people that are in here. As long as they are made aware of it, why does the public need to know.”* (HB13-57)

Heather: *“Yeah, we don’t make it a huge issue.”* (HB13-60)

Evonne: *“Why does it have to be out there in common knowledge? As long as it’s being dealt with by the hospital and with the visitors and the people concerned and the infection control people are made aware of it. I don’t know why it has to be made public.”* (HB13-57)

It is noteworthy that this view of a *C.difficile* outbreak not being of interest to the public was not voiced by any other focus group. This particular group of HCPs had also not experienced a *C.difficile* outbreak and stated that they had not had to deal with *C.difficile* very often in their ward area. This lack of familiarity with *C.difficile* could perhaps have impacted on such views.

What seemed to be most concerning and upsetting for HCPs about media reporting of *C.difficile* was that they felt that journalists always connected incidences or outbreaks with connotations of wrongdoing by HCPs. As a result, they commented that the media were responsible for engendering mistrust towards them. Additionally, a frequent complaint by many HCPs was that despite the fascination the media has with the occurrence and transmission of *C.difficile*, it was never counteracted by reporting any of the improvement work they do to prevent infection and reduce their *C.difficile* incidences, or the measures they put in place to manage and control outbreaks. In this sense, they believed that journalists have no interest in

positive stories or good news stories because they are not dramatic and would therefore not sell newspapers.

However, despite the recognition by some participants that HCPs have a responsibility to engage with media professionals so that improvement work and initiatives could be promoted, there were very few who stated they would be willing to do this. Indeed, in one focus group, they all stated that they would never talk to journalists because they believed if they did, their jobs would be jeopardised. While this fear may seem plausible from more junior HCPs, which two of these participants were, this viewpoint was also offered from a Senior Charge Nurse. Some HCPs stated that it was generally senior managers who were responsible for speaking to the media but they voiced their concerns about this. They felt that most managers did not actually know what was going on in their clinical areas, therefore they were not considered the most appropriate people to be providing the media with a correct representation of what was occurring.

Out of all the public and HCPs focus groups, only one identified a positive outcome of media coverage:

Adele: *"It's [media coverage] always a positive isn't it?"* (HB12-56)

Sharon: *"Yeah."* (HB12-54)

Lily: *“Yeah, a bit of both.”* (HE12-53)

Tracy: *“Because I think it gees up your staff and we’re able to say “look, we don’t want this happening in your area” but for the staff in the area concerned it makes staff morale rock bottom.”* (HB12-52)

Lily: *“I would like to say that they still put in the same effort into it, whether it’s publicised or not because if you have an outbreak...”*
(HB12-53)

Tracy: [interrupts] *“Oh we would yeah, but I wonder sometimes does it maybe buck up other healthcare workers in other areas, they’d think “oh god, this really is something pretty serious”.”* (HB12-52)

Lily: *“Yeah, they’d maybe be pretty mortified or embarrassed it being in the papers and their family and friends may question them about it as well.”* (HB12-53)

Considering discussions from all other HCP focus groups in relation to media coverage, it was evident that no-one else shared the view that sometimes the media can have a positive impact. Overall, media coverage generally appeared to be dismissed as being inaccurate and sensationalised, and was largely seen as being something that was beyond their control, rather than seeing it as an opportunity to act. There was an underlying sense that

participants believed that the media would report what they wanted regardless and there was nothing they could do about it anyway. One participant pointed out that stories come and go very quickly so he appeared to be unfazed and quite blasé about negative coverage. He stated that whatever the story was, it would pass quickly and the media would simply move on to another story and as a result, the news will be forgotten in no time. However, given the ease in which a number of newspaper stories were recalled, some of which were published some time ago, this perception could be questioned.

“The experts: to trust or not to trust?”

With regards to who the ‘experts’ are within the context of *C.difficile*, from the public perspective, they were thought to be all HCPs who are responsible for managing risks associated with *C.difficile* and keeping patients safe. As such, they were considered key risk communicators. Unlike participants’ perspectives about the media’s role in risk communication, there were contrasting views about how the experts communicated and of the level of trust they placed on the information being provided.

There was an overall agreement within and between public focus groups that there is a significant lack of appropriate technical information provided by HCPs about *C.difficile* for patients and public. This seemed to be the reason why most public participants stated they gained most of their information from the media. Although most discussions around expert communication were

related to hospital settings, it was also acknowledged by some that there is a lack of information in community settings, especially in GP practices.

It was evident in most focus groups that the public wanted more technical information of *C.difficile* such as what it is, what causes it, how it spreads and what can be done to prevent and treat it. Some participants acknowledged the effectiveness of posters in hospital ward areas to communicate information mainly around the promotion of hand hygiene. However, others felt that HCPs rely too much on posters to communicate information and encourage individuals to adapt preventative measures. This strategy alone they believe is ineffective as they stated they frequently observed people in hospital ignoring messages displayed on posters, such as hand hygiene requirements. Additionally, the lack of physical presence of HCPs to explain and elaborate on poster information, they believe encourages people to doubt the importance of the information, which is why they felt these messages are often ignored.

At times, there appeared to be a tension between the public and HCPs in terms of a hierarchical conflict which impacted on if and how information was imparted. For example, some of the public, mainly the younger participants and those from the outbreak area felt that HCPs deliberately want the public to remain ignorant about *C.difficile* so they do not ask questions. As a result, they believed that HCPs specifically do not go out of their way to communicate important information to patients and relatives. Another explanation offered

by some public participants for the lack of communication was that they felt HCPs did not actually know much about *C.difficile* themselves. There was also a sense that the public believe HCPs perceive them as a hindrance or a nuisance if they asked questions. Interestingly, it was those who were most critical about nurses and doctors in terms of attributing responsibility and felt more vulnerable, who voiced such perceptions. In the following excerpt, Betty recalled a situation where information was not forthcoming from a HCP:

Betty: *“Well, when I was in the high dependency unit after my operation, the nurse stood at the bottom of my bed and she said “do you know about C.diff?” and I said “No I don’t know an awful lot about it” and she said “Well I’m going to come back and talk to you about it”, but she never ever came back cos I had to go back down to my own ward in the afternoon so I must have missed her that way.”* (PB2-7)

Nancy: *“She could have found you but. She could have asked where you were. You know, they are not going out of their way then are they?”* (PB2-10)

Betty: *“No.”* (PB2-7)

Betty attempted to provide a rationale as to why the nurse did not return, but seemed to shy away from directly indicating the information was purposely not provided. However, as Nancy interjected and questioned if this was indeed a

plausible excuse, they agreed that this nurse should have communicated this information but perhaps chose not to.

However, not all experts deemed to be responsible for communicating information were viewed with such negativity. On the contrary, individuals who were perceived to be in an authoritative position and also knowledgeable and credible within the expert field of infection prevention and control, were held in very high regard. As a result, public participants stated that they always listen to information provided and respond favourably to information and guidance provided. Such individuals were also thought to be neutral in the sense that they were completely honest and open and did not favour a particular stance. What was notable however, was that the individuals that the public held in high regard, were not seen as knowledgeable or credible experts by the HCP participants. Rather they were thought to be the cause of further confusion and anxiety for the public.

For HCP participants, in addition to acknowledging themselves as experts who were responsible for communicating information, their conversations in relation to *C.difficile* communication were mainly focused around senior managers and the Government. Some HCP participants agreed with the public in that communication from HCPs was generally quite poor. This was discussed both in the context of communicating with patients and the public, and also communicating between themselves. Similar to perception of their competence however, HCPs did not see their own communication skills as

poor; rather it was other HCPs who did not communicate well or provide accurate information. For example, some HCPs explained that due to the high level of clinical activity in wards in other hospitals, there is often little or no time to communicate effectively with others. Additionally, as staff are moved around wards to cover those who are understaffed, they often do not have adequate knowledge of what is happening with some patients therefore they are unable to communicate accurate information about them.

However, in terms of their own communication, there were frequent in-depth discussions about strategies they adopted to ensure that they fully engage with patients and visitors. Additionally, they frequently reinforced the effectiveness of their own communication skills by stating that within their clinical area they always ensure everyone is aware of any issues, and infection prevention and control practice is adhered to at all times, such as good hand hygiene practices. With regards to communicating information to the public, some HCPs explained that they had their own websites and provided copious amounts of information about different types of infections, and what they were doing to address them. However, they stated that they felt the public in general are not likely to know where to go to find that information in addition to being able to interpret it correctly. Others agreed and stated that HCPs need to reconsider how information is communicated. Relying on other 'experts' to communicate with patients and the public was not seen as an ideal strategy:

Derek: *“Every year an expert tells you what you're going to die of after... then it doesn't happen. We had SARS, Bird Flu. Every year an expert tells you and they stock up on all sorts of vaccines and you think, are people getting the best possible advice? This may not happen. They're covering their backs to say this could happen, you could die next year, then it turns out it doesn't happen. So experts, I always find that when you hear an expert, they are normally pro or con an idea. They are very, very seldom a neutral expert and they're talking and you think 'I wonder who's paying their wage', I wonder who's behind them and they'll say anything. Or you'll get two experts - one says one, the other says another then they'll have an argument and I'm thinking, I just want the truth, but there is very, very few people tell you the truth because everyone is from one pressure group or another who will only ever tell you a bias point of view.” (HW11-47)*

Summary

The findings from the public and HCP focus groups illustrate the complexity of how and why individuals perceive and respond to risk factors that they associated with *C.difficile*. Often participants discussed issues that they directly related to *C.difficile* and other times, particularly in the absence of knowledge or direct experience, they provided evidence of a wider context in order to make sense of certain issues.

These focus group findings elucidate a range of factors that were important for both groups of participants in constructing risk perceptions and how they responded to risk in the context of *C.difficile*. They frequently described themselves as being frightened, frustrated, angry, upset and resentful about their experiences in which they saw as direct and indirect negative outcomes of *C.difficile*. Some of these outcomes, they also believed, had wider and longer term impact. For the HCP participants, this was also on a personal as well as a professional level.

While believing themselves to being placed in vulnerable positions, this allowed participants to attribute responsibility to individuals and situations. Although many of the public participants recognised that they had limited knowledge about *C.difficile* in general, they were very certain at times about who or what they blamed for various associated issues such as identifying specific poor practice observed by nurses and doctors which they believed contributed to the acquisition and spread of *C.difficile*. Although HCPs also claimed that certain situations contributed to *C.difficile*, they were less direct and specific about apportioning blame.

In recognising that the acquisition and spread of *C.difficile* was often due to wrong-doing, both groups of participants were very keen to segregate themselves from the wrong-doers and present themselves as competent individuals. In doing so, they claimed that they always did the right thing and never deviated from this. Healthcare professionals also further enhanced their

projection of competence by highlighting the obstacles that they have to overcome just to be able to do their job correctly.

In the final theme, evaluations of the communicators, participants placed much emphasis on the importance of appropriate risk communication and discussed in length two key groups of people deemed to be most responsible for communicating about risk: the media and experts. A general consensus was that there are marked variations in how risk is communicated, but a perception among many that this could be vastly improved. Discussions about the media were frequent, emotive and spontaneous by both groups, which confirmed the importance of this source in terms of gaining information and meaning making. The media were heavily criticised for sensationalist, dramatic and often incorrect representation and participants were quick to assert that they did not believe what was written. Paradoxically, however, media stories were often invoked in order to support claims being made and authenticate their accounts. In doing so, participants repeatedly moved into and out of acceptance of stories provided by the media, depending on whether these supported or challenged their own perceptions, preconceptions and experiences. For the public, risk information provided by experts was often called into question with some believing that perhaps the experts were not as knowledgeable as they should be or as they led people to believe. Some of the public were also very clear as to who they trusted, which interestingly was who the HCPs did not trust.

There were a range of determinants that influenced the way in which participants responded to risk factors that they associated with *C.difficile*. Availability heuristics were used frequently whereby participants often drew upon specific situations or events in order to make sense of certain issues or individuals. This was often through the recollection of direct and indirect experiences. Social influences were also found to be important, especially in relation to friends and family. However, what was of particular significance within social influences was the frequency with which the media was drawn upon and used to support or refute perceptions, despite frequent accounts of disbelief and distrust towards them. Being familiar or unfamiliar with *C.difficile* and associated factors was also found to be influential in that the less familiar they were, the less concern or worry they voiced. What was also notable was that a sense of place attachment provided a degree of protectiveness towards their local area and individuals which subsequently impacted on perceptions and responses.

These findings address significant gaps in the current literature as identified in Chapter Two. However, further gaps in relation to the role of the media in health risk reporting remain. So far, this study has enabled further understanding of how the media frame and represent *C.difficile* and key individuals within an outbreak situation. It has also gained an insight into ways in which such representation impacts on public and HCPs risk perceptions. In order to complete this media loop, the next chapter will present the media semi-structured interview findings so that an understanding of factors that

impact on how the media produce health risk stories in newspapers can be achieved. This will therefore enable a fuller picture of the role of the media on risk perceptions and responses to be understood.

Chapter Seven: Production of health-related risks in the media

Introduction

This chapter presents findings from the in-depth, semi-structured telephone interviews with media professionals. It sets out the participants' objectives in health risk reporting and key characteristics that they claim to be important in health-related risk stories. Additionally, it presents the influential challenges and constraints they face in health-related risk reporting in newspapers. This chapter addresses the fourth and final research question:

4. What factors influence the way in which health-related risks are produced in newspapers?

Profile of the media professionals

Ten media professionals were interviewed for this study, all of whom were employed by, or reported for, various newspapers within the UK such as broadsheets, tabloid, regional and local newspapers. Five participants stated they possessed a degree in journalism and the remainder stated they 'learned on the job'. Of the ten participants, all had heard of *C.difficile*, six had reported about *C.difficile* previously and one had personal experience of *C.difficile*. All participants stated that due to the nature of their job, in the sense that they needed to keep up-to-date with what is going on, they were readers of a wide

range of national, regional and local newspapers. Table 14 illustrates characteristics of those media professional participants.

Table 14: Characteristics of media professional participants

Participant	Gender	Age range	Length of time in job	Role	Newspaper
Ian	Male	36-45 years	14 months	Journalist	Tabloid
Dan	Male	46-55 years	20 years	Editor	Tabloid
Peter	Male	46-55 years	17 years	Journalist	Broadsheet
Emily	Female	36-45 years	10 years	Journalist	Freelance
Martin	Male	46-55 years	13 years	Journalist	Broadsheet
Sally	Female	36-45 years	5 years	Health Correspondent	Broadsheet
Gavin	Male	46-55 years	8 years	Editor	Broadsheet
Ryan	Male	46-55 years	20 years	Journalist	Regional
Abbie	Female	36-45 years	7 years	Journalist	Tabloid
Clive	Male	26-35 years	3 years	Journalist	Regional

As described in Chapter Four, two main themes and six subthemes inductively emerged from the analysis. Table 15 provides an overview of the emergent themes and subthemes.

Table 15: Media professionals' interview themes and subthemes

Main themes	Sub-themes
<i>Role in health-related risk reporting</i>	<i>"To report or not to report"</i> <i>"Analyse, probe and uncover"</i> <i>"Making the complex simple and memorable"</i>
<i>Challenges and constraints</i>	<i>"Getting the right information, from the right people, at the right time"</i> <i>"Whose agenda?"</i> <i>"Competing with others"</i>

Role in health-related risk reporting

Participants were very vocal and open about what they believe their role to be in health-related risk reporting and equally important, what they believe their role is not. They asserted that they were fully aware of the frequent criticisms of sensationalist, inaccurate or exaggerated reporting by various official sources such as HCPs, healthcare organisations, researchers and scientists. However, although most participants understood the reasons for these criticisms, they were keen to defend their positions as important risk communications and offer explanations as to why they report what they do and the way in which they do it. Most participants stated that because of these

criticisms, they feel that their role as health risk communicators is not fully understood or even appreciated.

“To report or not to report”

Perceptions of what was deemed to be a newsworthy health-related risk story were similar amongst all the journalists and editors. It was evident that the interest around a health-related risk story is stimulated more by the specific characteristics connected to the story rather than the actual subject. For example, when talking about the reporting of a *C.difficile* outbreak, it was not the infection itself or topic *per se* that was deemed to be most desirable. Rather it was the circumstances in which the outbreak occurred, in particular the involvement of specific individuals connected to it and how the outbreak came about. This was referred to by a number of participants as the “*story hook*”. There were various favourable health-related story hooks which were alluded to, but a common one was something that was a significant health threat pertaining to particularly vulnerable people or a whole community. Many also pointed out that the health threat needed to be unexpected, novel, surprising or out of the ordinary as Sally explained:

Sally: *I think it's difficult to get things in the paper, because if the editor's not interested - bowel cancer is a good example. Anything to do with bowel cancer, they're not interested. They're like "um, no, a bit icky, boring, we don't like it". So that's always a tricky one. C.diff is different, although it does kind of involve bowels! So um, they always see it as*

quite an interesting story so you don't always have any problems with getting c diff related stories into the paper as it's something that could have a big impact [...] So yeah, some subjects no, but I think C.diff is one of those that will always be a bit more interesting (M-74: Health correspondent).

A point strongly emphasised by all participants was that a good health-related risk story also had to be about people, and that it needed to have an “*it could be you*” human impact factor about it. This they believed, gained the most engagement among readers and got people talking to each other about it. For example, a health-related threat, such as a *C.difficile* outbreak, they ascertained, is of particular interest to people because people care about a major incident occurring in a hospital setting. They explained that because a *C.difficile* outbreak would be likely to affect significant numbers of vulnerable patients within a short space of time it would be emotive, which again would generate interest. Moreover, this interest would be further amplified if the outbreak caused a number of preventable illness and deaths, which would in turn evoke controversy, conflict and blame. A tabloid editor explained:

Dan: *“What you’re trying to do is introduce the human element. If it’s not about people, people aren’t interested. So you’re thinking about that all the time when you’re writing a news story. So, a C.diff outbreak in such a such hospital, yeah that’s interesting, but a bereaved mother who beat cancer and devoted her life to fundraising was then killed by*

C.diff after going in for a simple bloody operation, you know? She was going to get her ingrown toenail out then all of a sudden you've got a human drama, human tragedy. That's the stuff people identify with." (M-70: Tabloid Editor)

While other participants acknowledged that it is these types of stories that are likely to be criticised as being sensationalist or alarmist, they were quick to refute these criticisms as they stated they are simply reporting what has happened. In other words, they pointed out that it is the story itself that is "*genuinely sensational*" rather than sensationalist reporting.

Many participants stated they strive to obtain personal testimonies to further enhance the human impact. They claimed that personal testimonies were usually emotive anyway and were always a favourable part of their stories because people can connect more to this type of story than simply to journalists' accounts. Personal testimonies, they suggested, also attract imaginary engagement, encouraging people to remember what they have read and wanting to know more:

Emily: *"You know the story that's going to make the front page is 20 people have died in the Vale of Leven, or wherever yeah? In a features page, speak to a family that's lost somebody because of it. Those are always good stories. When a family comes to you and the public are now very much aware of how to work, to use the media. So you'll hear*

about a family and you've got a great story. You've got a heartbreaker on the front page." (M-72: Freelance Journalist)

Although these personal and emotive story hooks were popular with most journalists and editors, those working in local and broadsheet newspapers were a little more reserved in their descriptions of their ideal health-risk stories, referring to them as eye-catching case studies. However, all participants were clear that regardless of what newspaper they worked for, or what their role was, while human factor stories may give rise to sensationalist criticisms, the truth, without exaggeration, is always what they strive to report. For others, this was also in addition to ensuring that a balanced account of events was pursued. For example, if someone was being accused of misconduct, they would always ensure a "*right of reply*" is offered to the accused rather than simply printing a one-sided biased story.

Although tabloid journalists and editors echoed this perspective, they were more prescriptive about the need for stories to be entertaining and soap opera-like so that they would generate public interest, be a topic of conversation on a Sunday afternoon in the pub and generally get people talking about them:

Dan: *"There's an old journalistic expression: 'F*** me Doris!' If you've got a story that's a 'F*** me Doris', it's the idea that the bloke's sitting reading the paper and he says 'F*** me Doris, look at this!'"* (M-70: Tabloid Editor)

A key strategy of writing such entertaining and soap-opera type stories, according to Dan, is to ensure that the story has an “*engine*” and specific “*characters*” to keep the engine running. The media coverage analysis presented earlier provided an excellent example of this in terms of how different characters and identities were created and re-created over time as the story unfolded and new information came to light. Drawing upon personal experience of writing about a *C.difficile* outbreak, Dan explained that by creating this type of story, it allows him to move it forward by searching for different angles and new characters so that it keeps it interesting. This he stated also helps keep him ahead of the competition between newspapers.

While a risk story may continue to be interesting, participants explained that the extent that it holds the interest of the participants and its ‘newsworthiness’ is often dependent on another important factor other than who the story characters are. Some stated that health-related risk stories which implicate practice, or policy failings by individuals can be extremely powerful in shaping public and political agendas. Again, they pointed out that because most people have a vested interest in healthcare, this type of coverage is likely to get the public talking, encourage them to express their opinions and generate further controversy. This in turn often influences political responses and helps keep the story in the headlines. As a result, particularly for those working for tabloid newspapers, they explained that these are the situations whereby individuals are likely to contact them so that they can put their side of the story forward.

Indeed, one journalist commented that HCPs often go to the media as whistle-blowers because they know that they can make an impact without damaging their professional reputation. Although some participants noted caution when dealing with whistle-blowers, as they stated whistle-blowers may often have “*axes to grind*” or alternative hidden agendas, most tabloid newspaper journalists welcomed being contacted by this group of individuals. Some also stated that claims made by whistle-blowers can provide journalists with opportunities to explore new avenues or different angles. This they asserted can then lead to further interrogation of other individuals, organisations and government about the claims, all of which they believe is of interest to their readers. Without this level of interrogation, some participants stated that far too many health-related risks caused by wrong-doing would simply disappear under the radar. Clive, one of the journalists who initially ‘broke’ the news about a *C.difficile* outbreak in the media, explains the impact of his interrogation:

Clive: *“Yeah, I think if we hadn’t initially run the first story that was sort of mapping out local community concern about the fact that C.diff was in [hospital name] then the families wouldn’t have got in touch with us. Now, they might have got in touch with us some time down the line or a couple of them might have got in touch with the [newspaper name] some time down the line or whatever, but I certainly think if they hadn’t got in touch with us and we ran that story, and again a whole bunch of them, more of them got in touch with us and it kind of gathered*

momentum. I think if it didn't go like that, you know, I don't think it would have got to the stage of a public inquiry. I don't think you would have anywhere near the death toll the Health Board are talking about. I think the reason they put out that press release that way, you know, one dead, one infected on a bank holiday was a cover up. [...] We had that concern element for it straight away. People then got in touch with us then I think the way we sort of conducted our coverage, and what we tried to do with our coverage I think resulted in us becoming the go-to guys in it all which obviously it helped with our paper.” (M-78; Regional journalist)

What was also evident from the participants accounts were that while they were clear about their role when reporting a health-related risk story, they were also keen to emphasise what their role was *not*. All participants were clear that their job was not to ‘educate’ the public on any of the technical issues of a health risk. Rather, they were there to simply tell the public what was going on. For example, in the context of *C.difficile*, no journalists or editors saw it as their job to provide technical details about the organism such as what it is, how it is transmitted, how it is treated and how people can prevent infection. As one journalist explained, *“it’s not our job to tell people to wash their hands before they go into hospital and all the rest of it”*. Another journalist also added that it was not their job to provide helpline numbers either. Simply, their job is to *“report what really happened”*.

“Analyse, probe and uncover”

In many interviews, there were, at times, illustrations of tensions and ambivalence between journalists and the sources they used, due to the arousal of suspicion over the information being provided (or not being provided) by the source. The NHS was one source which appeared to arouse a great deal of suspicion for participants. One journalist commented that with regards to a *C.difficile* outbreak, the NHS do not report it until a long period of time after it has started. Most participants stated that disclosing information at such a late stage is likely to make them believe that something was being deliberately hidden from them or covered up. As such, they explained that their job is to analyse the information provided to them, and then to probe further to ensure that the “*wool was not being pulled over people’s eyes.*” In this sense, they likened themselves to watchdogs or advocates for the public.

A number of participants stated they felt frustrated when seeking information from the NHS. They explained that they believe the NHS often deliberately uses complex scientific jargon that they think journalists will not understand in an attempt to hide or gloss over certain information. However, rather than this strategy acting as a deterrent for reporting, it seems to have the opposite effect. For example, one journalist asserted that he would not take information provided by the NHS at face value and simply report what he was told. Rather, he would make it a priority to dig deeper to find out what they were trying to hide, if he felt that they were. Another journalist also illustrated this point in relation to the Vale of Leven *C.difficile* outbreak:

Ian: "I suppose if there's any hint of a cover up. I guess, you know, Health Boards and the Scottish Executive are very sensitive around these issues, um, a lot of time because there are big political issues as well. You often find that, or sometimes, rather than they try and gloss over some of the issues involved and try to play down the important stuff. [...] The Vale of Leven is a good example in the sense that it wasn't... the full facts weren't made clear straight away and it involved a lot of prying to get the full picture out and you know, that shouldn't be the case because it's people's relatives." (M-69; Tabloid journalist)

Most participants acknowledged that because the outcome of their probing often leads to further reporting of controversy, their stories are often viewed as dramatic, sensationalist and scaremongering. However, it was strongly emphasised by many that they take great pride in their skills and ability to be able to achieve this, and to decipher often complex and ambiguous information:

Gavin: "So partly we are conduit for what officials are saying but we also have a duty to interrogate that - what they are saying and question its veracity and point out, using our judgement and the judgement of um, any experts that we can get our hands on - to question the way anything has been dealt with, or if the information that's come out is indeed an accurate reflection of the situation or if it's actually an attempt

to put a gloss on a situation that may indeed be worse [...] So, you know, a journalist will kind of, look at things at face value, they'll question it but they will also want to know, if this goes tits up, as things can do, you know, what's the risk? So I think that's when we kind of get ideas of, what some people would describe as scaremongering. But, you know, the other way of looking at it is not just simply docile acceptance of what officials are saying. We're intelligent and what we do is we take reality and analyse it. We don't just kind of put it unmitigated into the newspaper. Our job is to kind of, journalism is a process of selection, choice and also presentation. You know, and all those things carry valued judgements and we regard it as bring our skills to raw material.” (M-75: Broadsheet editor)

“Making the complex simple and memorable”

Making complex, sometimes highly scientific health stories simple and memorable was considered a key factor by most participants in the pursuit of a good news story and, most importantly, to be able to engage with the reader. However, it was strongly emphasised that journalists and editors are not scientists, doctors or nurses, therefore they do not possess the in-depth technical knowledge or understanding about certain complex health-related risks. Indeed, when asked about *C.difficile* during the interviews, although many had heard about it through outbreaks and some had reported about it, they admitted to having little microbiological knowledge. They stated that this lack of understanding can make their job significantly more challenging in

terms of having to make sense of information provided to them, particularly from the NHS and HCPs, then simplify it in a way which would be understood by the public. Some acknowledged that for this reason, they appreciated that perhaps the more technical information that is reported may not be completely accurate. However, they added that because they are able to simplify such complex information, they believe this is why the public use the media as a main source of health information rather than the NHS or the government:

Emily: *“You know, when I talk to even NHS communications people, and say ‘right ok, you’ve told me something and it’s full of jargon, now do it tabloid’ and they can’t. The ability to explain yourself clearly and succinctly is you know something that kind of gets knocked out of some people I think.”* (M-72: Freelance journalist)

In order to report health-related risk stories in a way that will be of interest, understandable and memorable for their readers, many participants explained that the presentation of stories and the language used are crucial. For example, they asserted that if the reader has to work hard in order to make sense of a story, then it may well be ignored, dismissed or quickly forgotten. Therefore, they asserted that their stories need to be easily understood. This is exemplified by Ian, a tabloid journalist who spoke about a friend who worked in a healthcare setting:

Ian: “Ah, yeah, it was, it was norovirus, um. It was really interesting talking to her to understand how it [the NHS] works internally. [...] But it was quite interesting because she took issue with a story that the [newspaper name] did cos um, she said, you know it was alarmist. I flicked through it and I was just like, ‘it’s not alarmist because every single aspect in the sentence, there is a fact, you know ‘a killer superbug that sweeps through hospital’, you know I think she just didn’t understand the language that this paper had used so people would read it you know, and she couldn’t understand how they hadn’t gone chronologically through the incident, the facts. And I was sort of explaining, you know, it’s not a book. People need to get the most pertinent facts first.” (M-69; Tabloid journalist)

This point was echoed by others, particularly those from tabloid newspapers:

Martin: “Essentially, you’ve got to get what you think is the main angle of the story, and you boost that up in your first one, two, three paragraphs as much as you can because you think that is the one that’s gonna catch the people’s attention. You know, if you say, um ‘A man was jailed for three months yesterday for a charge of theft committed at Marks and Spencer’s, in Edinburgh’, well, I’m sorry, but **yawn!** Who on earth is gonna read further than that?! [...] You know, if it turn out it was a transvestite who was stealing ladies underwear, you know, I’m sorry, it’s probably the wrong example, but that then turns into

something more than a man who was jailed for stealing from Marks and Spencer. You know, you hammer that aspect of it because you think that's gonna be the line that's gonna catch people's attention. That's the line that's of interest to the public. People are then much more liable to say, standing in the pub having a pint after their work 'Oh, I saw that story about the man nicking the woman's knickers from Marks and Spencer' rather than 'Oh, I see someone got jailed for shoplifting in Marks and Spencer'" (M-73: Broadsheet journalist)

Some participants admitted that they understood why these strategies for reporting are often misconstrued as being sensationalised and inaccurate. However, they believed such perceptions to be an outcome of people's lack of understanding of the role of the media. Despite this, a crucial point, most were clear about was that they would never intentionally report an inaccurate story or even "*bend the truth*". However, they stated that they have a job to do in the sense of "*telling a story*" and they also have to respond to the requirements of the newspaper and ultimately the editor. Writing a completely neutral, balanced, objective story, most asserted, does not fit with their role as a newspaper journalist or editor.

Challenges and constraints

While journalists and editors clearly vocalised what makes a good health-related risk story, and indeed what does not, they commented on a variety of factors that influence coverage.

“Getting the right information, from the right people, at the right time “

One of the most challenging aspects of health risk reporting for most participants is gaining the right information from the right people at the right time. Many commented that there is no control over when a health-related risk story transpires. As a result, they could potentially be asked to produce a full story of a complex health-related risk situation within a very tight timescale. One journalist pointed out that this could be as little as 45 minutes.

The more experienced journalists stated that this is less of a challenge as they have built up a diverse range of trusted contacts over the years who they know they can call upon at any time. However, for the less experienced and established journalists, and those working in local or regional newspapers, this can be particularly problematic as they have not been in the role long enough to have generated such contacts. As a result, sources they end up locating may not be the most appropriate ones to provide the information needed which can impact on the information that is reported:

Ryan: *“If you know the key person who to speak to, ideally to get expert comment on the story, but if you can’t get them before 4pm and 4pm is your deadline, then you go and speak to someone else who’s less good or less well informed, but who can speak to you in time for your deadline.”* (M-76; Regional journalist)

In relation to health-related incidents such as outbreaks, regardless of the newspaper they worked for, most participants stated that the most sought after sources are patients or families. They asserted that personal testimonies achieve far more reader engagement than official or scientific information provided by experts because it personalises the story, making it more engaging for the reader as it puts the story into context. Participants explained that their readers relate to these types of sources far more than experts or officials providing technical or statistical information. Additionally, some participants stated that they tend to shy away from NHS experts anyway because they are so problematic to deal with:

Emily: *“I continue to be stunned about how badly the NHS communicates with the general public and the only way to do that is through the media. Um, you know, people don’t want.... You’ve got all sorts of different drivers. I mean, doctors don’t like to stick their heads above the parapets because other doctors think they are being... showing off. Nurses don’t like to stick their heads above the parapets because they don’t feel they are empowered to. Somebody, you know, there’s a suspicion that somebody will come for them. Who? Why? I dunno. Um, managers don’t like it because it bloody well gets in the way and it’s a damn nuisance and ‘why does anyone want to know – it’s their business anyway’. So you’ve got all sorts of hideous cultures inside the NHS that make it difficult.”* (M-72: Freelance journalist)

Other participants echoed this perspective and further added that The Freedom of Information Act eases the pressure for them slightly in terms of requesting certain information from NHS communication teams, such as infection figures. However, some explained that obtaining access to more intricate details from the NHS about specific situations is always almost impossible as Emily went on to explain:

Emily: *“They treat the media like shit and you cannot win that way. They are control freaks. They want to take control of everything and it backfires on them badly.”* (M-72: Freelance journalist)

One of the most discussed reasons during the interviews for such obstructive behaviour by NHS communication teams was the lack of knowledge and understanding of the role of the media, as Emily further highlights:

Emily: *“Communication teams in the NHS are particularly crap in most cases. They don’t know journalists, they don’t know journalism, they don’t know what’s wanted and they are very defensive.”* (M-72: Freelance journalist)

By employing such defensive tactics, rather than stalling or preventing media reporting, most participants highlighted that this is simply counterproductive as it only serves to instil suspicion that something is being hidden. Once suspicion has been aroused, journalists explained that they would continue to probe until they uncovered what they believe the NHS is attempting to hide.

“Whose agenda?”

Although all participants were agreeable that using sources in health-related risk stories were a crucial element to making it newsworthy and interesting, several pointed out the need to exercise caution when using certain sources. Despite detailed explanations provided to sources about what information they are looking for, many stated that they have experienced sources to be more interested in exploiting the media in order to raise the profile or their own agenda. As a result, participants explained that they may not receive the most appropriate information:

Martin: *“I’m sorry to say I have had to take the easy option out on occasion where my office will say ‘right, here’s a story, get reaction to it’ and you think ‘oh god, I’m gonna have to phone some MSP who will give me some drivel that you know is absolute tosh and they don’t know why this question you’re asking, but that’s the point they want to put across”.* (M-73: Broadsheet journalist)

Martin went on to explain that because more often than not, they do not have the luxury of time where they can then try to locate a different source in order to gain the information they require. This can have implications on how the information provided by the source is used and how the story is ultimately presented.

The participants stated that whistle-blowers are particularly interesting and relevant sources for the media because they are often instrumental in capturing elements of wrong-doing, conflict and cover ups within healthcare, particularly around outbreak situations. Additionally, a whistle-blower's story can provide the media with new and unexpected angles to a story which puts them ahead of other journalists and newspapers. As such a whistle-blowers' story could potentially have a major impact on perpetuating public interest. However, some participants stated that understanding a whistle-blower's motivation for telling their story to the media is extremely important in determining whether or not the person, and the information provided can be trusted. Some participants stated that extreme care is always needed when reporting accounts provided by whistle-blowers. On the one hand, they asserted that that their primary obligation is to report the truth about what is going on and expose those who are guilty of wrong-doing, without the risk of pernicious repercussions for the source, especially if they did not want to risk losing whistle blowers as future sources. On the other hand, they went on to explain that they had to ensure their own professional credibility and the credibility of the newspaper is not damaged in any way. Participants perceived that motivators for some whistle-blowers, other than simply reporting wrong doing could be that they have a personal or professional "*axe to grind*" with others or simply for financial reward. To gain reassurance and verification about a story, such things like documentary evidence is often requested by a journalist. However, one journalist commented that often the time and effort it

takes to do this is more hassle than it is worth and suggests that perhaps this is not undertaken as thoroughly as it is needed.

“Competing with others”

The existence of some competition between newspapers and journalists was evident within all interviews. However, perhaps surprisingly it was not in relation of being the first to “*break a story*” or to get the best “*scoop*”. Due to other news outlets such as the press association wire, 24hr television news, the internet blogs and Twitter, it was largely accepted by most participants that “*newspapers can’t break the news like they used to*”. Consequently, due to the interest in health-related risk stories, most newspapers would cover the same risk story anyway:

Ryan: “*These things have a sort of momentum. There can be a sort of pack mentality. It’s not necessarily desirable, but there is a sense that if... it’s kind of, a service to the readers in a sense. If lots of people are talking about something, it’s odd if another newspaper or other news outlet choose not to cover it you know, because the job is to tell people the news and if things are being discussed elsewhere, often it means other titles will want to discuss them as well.*” (M-76: Regional journalist)

However, Ryan went on to comment about being cautious not to step on another newspaper’s toes as this may also impact on professional reputation. As a result, he suggested that some may not even cover a story:

Ryan: *“With exclusives, if one paper takes ownership of an issue, then the others may not. If it’s too closely identified as their story, others may not for fear of kind or, er... being led by a rival brand I suppose.”*
(M-76: Regional journalist)

However, no other journalist or editor offered this view. Rather the majority stated they would still report about the story, but try to find a different angle by contacting different sources. One journalist stated that *“the drive to be different often sacrifices the best line of the story”*. In other words it can potentially have a detrimental effect on the published story. Another participant added that because most journalists are not health specialists and do not possess health related knowledge, in order to find that different angle, they often find themselves *“running around like headless chickens not really caring whether it [the story] was true or not”*. One participant explained that the potential consequence of this is that the journalist’s story ends up exaggerated or dramatised in order to make it better than their rival’s story:

Gavin: *“[...] You know, that carries inherent risks and you end up just looking stupid, especially, you know, not just with your rivals, but with other broadcast outlets and if everyone else is saying there’s a one in hundred chance of something happening and you’re saying there’s a one in thirty chance of it happening, and you’re the only one that’s saying that, you end up looking foolish.”* (M-76: Broadsheet editor)

While none of the participants in this study stated that this was a tactic that they themselves used, some believed that others do.

Summary

The journalists and editors interviewed for this part of the study were clear that their role is simply to inform their readers what was going on, to keep them up-to-date and to some degree, to entertain them. Moreover, they were clear that their role was neither to 'educate' them about health matters nor to echo policy makers' guidance. In order for a health risk issue or event to be newsworthy, participants asserted that it must have a good story engine or hook. In addition to this, interesting characters are also necessary in order to keep it alive and personal and for journalists to be able to move it forward. Without this, it is unlikely to capture reader interest and, therefore, will not generate public discussion or be memorable. However, due to the complexity of many health-related risk issues, media professionals require engagement from a diverse range sources in order to be able to communicate in an accurate, open, honest and transparent way. This at times, appears to be challenging to achieve given that there is a degree of competition between journalists to locate new and different perspectives on a story through the use of their sources. This can be further constrained through competing agendas by others and working to sometimes, very tight deadlines.

The findings of the interviews with media professionals has enabled this study to look beyond a critique of media representation and explore important factors

that impact on the way in which health risk issues are produced in newspapers. In doing so it enables an understanding of the wider picture of how information about *C.difficile* and health-related risk issues are communicated via newspapers. This understanding can now help generate greater insight into how the media can help shape individual risk perceptions and responses not only in relation to *C.difficile*, but also of wider health risk issues.

The next and final chapter of this thesis will discuss the implications and contributions of this study.

Chapter Eight: Discussion

Introduction

This chapter begins by presenting a brief summary of how this study was undertaken. It then provides a reflection on the methodological choices that were made before moving on to explore some of the key findings with reference to the wider literature, and discusses the implications for practice, policy, education and direction for future research. The chapter concludes with a personal reflection.

Revisiting the research questions and study approach

The aims of this study were to explore public and HCPs' risk perceptions and responses in the context of *C.difficile* and to examine the role of the media in health-related risk reporting. In order to address these aims, the following research questions were formulated:

1. How was information about *Clostridium difficile* and associated individuals framed in the newspapers during an outbreak?
2. How and why do the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?
3. Are there similarities and/or differences in the way the public and healthcare professionals perceive and respond to risk factors they associate with *Clostridium difficile*?

4. What factors influence the way in which health-related risks are produced in newspapers?

To answer these questions, the following research process was undertaken:

- Four literature reviews in the form of two scoping reviews and two structured reviews. The scoping reviews examined wider risk perception literature and also risk reporting in the media. The structured reviews examined risk perception literature specifically pertaining to *C.difficile* and other healthcare associated infections. One review examined this from public and patients' perspectives and the other from HCPs' perspectives.
- A media coverage analysis of a major *C.difficile* outbreak which occurred in Scotland in 2008 in order to examine media representation.
- Focus groups with the public and HCPs from two geographical locations: the West of Scotland where there has been a highly publicised *C.difficile* outbreak and in the East of Scotland where there has been no outbreak. These focus groups explored risk perceptions and responses of the public and HCPs associated with *C.difficile*.

- Semi-structured in-depth telephone interviews with media professionals to examine factors that influence health-related risk reporting in newspapers.

Reflections on methodology and method choices

This research was undertaken using a specific philosophical and methodological approach. It was congruent with a social constructionist approach, ID methodology and qualitative methods as multiple perspectives of risk perceptions were sought. However, it is appreciated that there are other approaches, both qualitative and quantitative, which could be used. For example, for researchers attempting to measure perceptions of risks around a certain activity then a quantitative approach using a positivist philosophical underpinning would perhaps be more appropriate.

Deciding on the methodological choice for this study was particularly challenging and took a considerable amount of time. During the early stages, specific methodology was not given a great deal of consideration other than broadly there was to be a qualitative approach. As time progressed, and time was spent reading around different qualitative methodologies, questions were quickly raised with regards to the congruence of each qualitative methodology with the philosophical positioning, the research questions and the ideas for the research methods of this study. This led to taking some 'time out' just to focus on qualitative methodological reading. It was then that it became clear that all the dominant qualitative methodologies did not fit with many aspects of this

study which caused significant concern and frustration. However, through perseverance with more searching and reading, ID was learned about, and through time, it was apparent that ID fitted well with what this study was trying to achieve. In particular, it was reassuring to note that ID was developed for nurse researchers who were seeking to develop empirical research which did not fit with other methodologies. This methodology was also designed to account for the clinical context of the research. For example, as explained by Hunt (2009), expert clinical knowledge is seen as a solid platform for nurse researchers particularly where there is little empirical data about a specific health-related issue. Furthermore, ID is advocated for use when the product of the empirical inquiry can contribute to clinical practice. Thus, using ID allowed the researcher's clinical experience to help guide the process of inquiry for this study so that findings could contribute to improving clinical practice. Finally, the ontological and epistemology positioning grounded within social constructionism fully aligned with ID in terms of understanding that realities are socially and experientially based. Taking these issues into consideration, the use of ID was appropriate, coherent, practicable and pragmatic.

The HCP participants for this study largely consisted of nurses. It was initially aimed to generate a wider professional sample, for example medical and managerial staff. Failing to generate this wider sample may have been influenced by the recruitment technique adopted (through the use of

gatekeepers i.e. ward managers). However, the aim of this study was to generate in-depth understanding of risk perceptions and responses, which was achieved with this sample.

As illustrated on the participants' questionnaires that were completed prior to the focus groups and interviews, a range of demographic characteristics were obtained. Some of these characteristics, for example religion, salary, race and level of education, appeared to have little or no impact on risk perceptions and responses within this study. It was felt important to include these as initially the questionnaire was developed to also aid purposive sampling and therefore, to select participants with a range of characteristics in order to reflect diversity among individuals. As all participants who expressed an interest were recruited, the characteristics were not used for sampling. Therefore for future research, the collection of demographic characteristics should be undertaken only if there is an indication that they are important.

It is accepted that the use of qualitative methods are not without challenges. Participants taking part in focus groups may not always express full or honest opinions about a topic, particularly if they oppose the views of other participants. Additionally, some focus groups can be dominated by more vocal participants who may stifle others' contributions, therefore this must be recognised. Nevertheless, it is established from the literature review that risk perceptions are socially constructed therefore using focus groups enabled the illumination of the way in which participants interacted with each other, shared

their views with others, made sense of issues and how this social interaction impacted on how they constructed and modified their perceptions.

Additionally, most media professional data was generated through telephone interviews. This was largely chosen for pragmatic reasons in terms of their geographical spread, and the nature of their work in that they could have been called away at any time which would immediately terminate the interview. While telephone interviews have many positive qualities, the main limitation is the absence of observation of non-verbal language which in qualitative research is an important part of data analysis. Fortunately, most journalists and editors were very vocal and animated during the interview with few pauses or silences, therefore not being able to visualise non-verbal language did not appear to impact on the quality of data generated.

It is established that the term risk perception is a complex one and not a term that is widely used by people every day. A common problem for focus groups is that the moderator may ask questions in a manner that can potentially influence participants' responses. For this reason, a concerted effort was made in focus groups not to use the term 'risk perceptions' when asking questions or probing. On reflection however, it may have been beneficial perhaps at the end of the focus groups to ask participants what the term risk perceptions meant to them so that assumptions made by the researcher could be supported by further evidence. Moreover, it may have been beneficial to invite public members and HCPs to participate in the research process such

as developing the focus group topic guide, or even help with the generation of data.

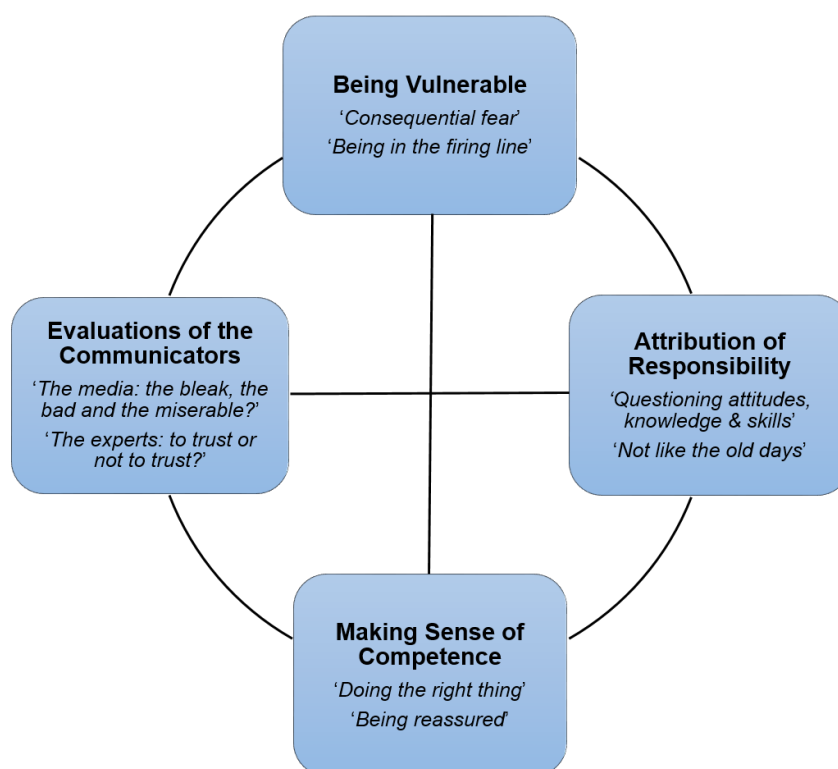
Finally, it is accepted that newspapers are only a small part of media sources in terms of risk communication. Due to the scale of this study and constraints of time, it was decided only to include newspapers. The findings of this study may have been limited by the decision not to include other media sources, such as television or the internet on risk perceptions. However, given that the purpose of the media coverage analysis was to gain an insight into how *C.difficile* had been communicated during an outbreak, newspapers were considered to be most appropriate at that time.

Examining key findings with reference to the literature

Having considered the findings of this study, the complexity of how and why individuals perceive and respond to risks in the context of *C.difficile* is apparent. This complexity could provide an explanation as to why there is limited risk perception empirical research within the context of *C.difficile*. This study, therefore makes a significant contribution in this field. What emerged from the focus groups was a conceptual framework that provides a generic account of how people construct and communicate about risks through conceptual categories, and fleshed out in the detailed context of *C.difficile* through underpinning themes. In other words, the framework provides a coherent and structured way in which individuals think about risks, and

demonstrates how this was applied in the context of *C.difficile*. This conceptual contribution is represented schematically in Figure 8, which also illustrates that each element of the framework is co-dependent on each other.

Figure 8: Conceptual framework of risk perceptions



The following section now considered the elements of the conceptual framework in relation to the wider literature.

Being vulnerable

There is a tendency within the wider literature to refer to susceptibility when seeking to understand risk perceptions (Taylor et al. 2006, Orji et al. 2012,

Carpenter 2012). This largely appears to be informed by social cognitive frameworks, namely the Health Belief Model as discussed in Chapter Two, whereby perceived susceptibility is believed to be a motivational engine for a person to adopt precautionary behaviour towards a risk (Al-Dubai et al. 2013). For example, if an individual believes they are susceptible to a health-related risk, then they are more likely to take appropriate action to prevent the risk from occurring. However, the findings of this study suggest that a person's perceived vulnerability is more pertinent to risk perceptions than perceived susceptibility.

Although the terms susceptibility and vulnerability are at times used interchangeably within the risk perception arena (Sychareun et al. 2013), the findings of this study demonstrates that they are two separate entities. In the context of *C.difficile*, the term susceptibility would refer to a person's judgement relating to perceptions about the chances of acquiring it. Vulnerability, however, encompassed a much broader range of perceptions in that it captured beliefs about the perceived consequences of *C.difficile* occurring and the impact that the consequences may have on themselves and others.

Based on the findings of the public and HCP focus groups, it was evident that subjective beliefs and experiences were key factors which impacted on how vulnerable participants felt. Furthermore, through the sharing of often very detailed and emotive observations and experiences, the strength of this

vulnerability was particularly notable. Both public and healthcare professionals' experiences being a key part of assessing the performance of healthcare systems and informing quality improving processes has featured widely in the literature (Wilcock et al. 2003, Davies and Cleary 2005, Hogan et al. 2011, Tsianakas et al. 2012, Lee et al. 2012). For example, Tsianakas et al. (2012) examined the value of detailed patient narratives in identifying priorities for improving breast cancer. They used the Experience-Based Co-Design approach in which one of the main components is to use patient narratives to capture and understand patient experiences of their care pathway and to identify 'touchpoints'. The touchpoints are crucial good or bad moments during their care that shaped their overall experience. The study found that using patients' narratives helped delve into a problem and elicit critical cues which then helped identify potential solutions and inform the next steps for service improvement. This suggests that recognition of the experiences identified in this current study could be hugely important in helping improve risk management and communication in relation to *C.difficile*. What this current study further added in relation to experiences, was the observation of the way in which participants interacted with each other and accepted each other's narratives often without question or doubt. This demonstrated how powerful sharing experiences were in enhancing engagement. The findings of this study suggest that the use of personal experiences could be an effective way to communicate risk issues around *C.difficile* and also wider health-related risks.

There was a widespread agreement among the public participants that *C.difficile* was a dangerous infection, which could cause very serious illness and ultimately death. Vulnerability from this particular group was conveyed in terms of being fearful for themselves and family members about being potentially exposed to *C.difficile* while in hospital as patients and/or visitors. For example, significant concerns were consistently raised about the perceived lack of cleanliness and poor hygiene in hospitals, in addition to poor infection prevention and control practice by HCPs. These factors, among others, they believed were heavily associated with the acquisition and spread of *C.difficile*. As a result, many spoke about the additional actions they took to protect themselves, such as cleaning hospital equipment themselves or even avoiding certain hospitals altogether.

There was however a sense that *C.difficile* seemed particularly dangerous, real and relevant to those in the West (outbreak area). The most plausible explanation for this could be the experience of having an outbreak occur in their local community. This concurs with the findings of wider risk perception literature whereby the closer a person feels to a particular risk, the higher level of concern about the risk is likely to be expressed (Tilburt et al. 2011, Holman et al. 2014). Additionally, the more serious the outcomes or consequences of the risk is perceived, the more concern a person will have about the risk (Bond and Nolan 2011). This also aligns to one of the elements within the Health Belief Model discussed in Chapter Two in that if a person believes that the

consequence of a health-related risk will be severe, then they will be more likely to take preventative precautions (Janz and Becker 1984).

The current study also further strengthened this thinking as it found that although the public participants in the East (non-outbreak area) also considered *C.difficile* to be dangerous and serious if it occurred, the level of perceived vulnerability did not appear to be as strong and emotive as it was by the participants in the West owing to not having experienced *C.difficile* in the same way. Furthermore, Mottram (2012) claims that such concerns are often perpetuated through frequent and consistent exposure of it in the media, particularly if coverage continues to convey further uncertainty. Given that the outbreak in the West generated a significant amount of media coverage, which was at times contradictory, as identified in the media coverage analysis in Chapter Five, this study supports such claims.

However, demonstrating the complexity of risk perceptions and responses, a contradiction to this assumption is also noted in the wider theoretical risk perception literature as discussed in Chapter Two, which relates to familiarity. The concept of familiarity within this literature reveals that the more familiar someone is about a risk (often through exposure to the risk), then the less concerned they may become about it (Bickerstaff et al. 2006). This can have challenging implications for risk communication in that if the message is aiming to alert people to a potentially dangerous risk in an attempt to encourage them

to take certain precautions, they may often dismiss such messages as alarmist.

What was also important was that despite those in the West showing more concern about *C.difficile* than those in the East, there was still a sense of protectiveness towards the local community and hospital. This seemed to be rationalised by the belief that the community and hospital have been stigmatised since the outbreak had occurred. This protectiveness is supported to some extent by the literature, although it is not straightforward. Williamson and Weyman (2005) and Evans Cameron (2008) assert that an emotional bond is often created through social relationships within communities that are affected by a risk because of their history of shared experiences. Evans Cameron (2008) further adds that as a result of this emotional bond, regardless of the risk, individuals are less likely to be concerned about the risk and actually focus more on protecting their territory. This evidently contradicts the notion offered by Prelog and Miller (2013), that people living in geographical areas that have endured a risk generally, express higher levels of concern or vulnerability. The findings of this study suggests that while geographic location can have an important impact on the level of vulnerability expressed and perceptions of risk, it needs to be considered in conjunction with other subjective factors such as attributions of responsibility, judgements of competence and evaluations of risk communicators.

A fundamental factor that the public attributed for their heightened vulnerability about *C.difficile* was a significant lack of knowledge and understanding. Additionally, this was the reason they stated that most of the information they gain is from the media. Such an assumption is certainly congruent with some authors. For example, Zhang et al. (2012) reported that not being knowledgeable about a health-related risk led to 'irrational' risk perceptions and failing to adopt recommended preventative precautions. Similarly, Brug et al. (2004) found that being knowledgeable about a health-related risk led to 'rational' risk perceptions and the adoption of appropriate preventative precautions. It could be argued, however, that this is a fairly simplistic view of something that is clearly complex as current literature demonstrates, even if a person is considered knowledgeable about something, this is not an indication that their behaviour will reflect that (Albano et al. 2014, Lee et al. 2014). In other words, they may know how they are expected to behave, yet they fail to do so due to external influences and risk perceptions.

Others also assert that individuals who have little knowledge and understanding about risks, often form their perceptions around previous personal experiences (Cho and Lee 2006). Eiser (2004) further adds that it is not unusual for those previous experiences that are drawn upon, not to resemble the risk in question. Rather, the key issue is that these previous experiences trigger associated memories and emotional reasons which then help individuals to make sense of an uncertain risk. This is often associated with availability heuristics (McDowell et al. 2013), also discussed in Chapter

Two. As a result of this, following exploratory risk perception empirical work, as lack of knowledge is commonly reported, frequent recommendations of more education is often put forward (Mattner et al. 2006, Collins et al. 2009, McLaughlin et al. 2008).

Within the context of *C.difficile*, while this literature appears to suggest that by being more knowledgeable about *C.difficile*, could potentially alleviate public concern, and perceived vulnerability and also ensure preventative precautions would be adhered to. However, the findings of this study demonstrate that despite the public asserting that they lacked knowledge about some aspects of *C.difficile*, they actually appeared to be quite knowledgeable and certain about a number of important factors which they believed contribute to its acquisition and spread. Furthermore, they were also confident about what precautions are necessary to prevent the spread to *C.difficile*. Yet, their strong sense of vulnerability remained evident. The findings from this study therefore raise questions about the extent to which a lack of knowledge affects the perceived level of vulnerability and the subsequent adoption of preventative precautions. Consequently, it also raises questions about the potential efficacy and impact on vulnerability following the provision of more 'education'. This reinforces the need for 'meaningful' information rather than simply 'more' information.

Demonstrating the complexity and fluidity of risk perceptions in terms of vulnerability, some elements of this study further question the simplicity of the

above claims made in the literature as inconsistencies between risk perceptions of *C.difficile* and subsequent actions taken to prevent infection were noted. For example, in an initial discussion between three retired women, two stated that they would not be specifically afraid of *C.difficile* if they were to go into hospital. Yet, later on in the discussion, they spoke about the extreme measures they took to protect themselves when they go into hospital such as taking in cleaning wipes and gels to clean equipment and taking a bottle of Dettol to clean toilet seats (Chapter Six). Such behaviour would indicate that these women were in fact fearful of *C.difficile*.

Two factors could account for the apparent disparity between their risk perceptions and their actions. First, when the two women first stated that they were not afraid of *C.difficile*, it was relatively early on in the discussion. However, as the discussion progressed, other members of the group shared accounts of their negative experiences of healthcare, particularly around poor cleanliness. Their accounts also appeared to be strengthened and to some extent validated, as they aligned them with previous media coverage. Another participant in the group further contributed to this discussion by sharing explicit details of the severity of her illness after she contracted *C.difficile* numerous times. It could be argued that through such emotive accounts, the perceived risk of *C.difficile* perhaps seemed to become more relevant and tangible compared to early, more general discussions which could account for what seemed like a change of perception by the two women.

Similar inconsistencies between perceptions and actions are noted in the wider literature in relation to how health-related risks can be created and re-created through shared experiences and perceptions (Finucane and Holup 2005, Russell and Babrow 2011). The relevance here, as pointed out by Conrad and Barker (2010) is that the reality of a health risk does not simply exist in the world waiting to be discovered. Rather it is created by individuals who enact their experiences and perceptions, endow it with meaning and share this meaning through interaction with their social world. As a result, when individuals share with others more intimate details about a risk, it makes it easier for people to mentally simulate what an event will be like, so they generate vivid imagery of the event. This can also encourage others to bring to mind events that perhaps have been forgotten over time (Van Boven and Epley 2003). This literature and the findings of this study, are particularly important as it seems that people are more likely to respond to a more personal account of risk messages than more formal, objective ones. Additionally, this could perhaps explain why personal testimonies within media coverage are particularly powerful in influencing risk perceptions.

A second potential explanation could be considered through the relationship between risk perception, risk response and the notion of controllability as discussed in Chapter Two (Sjöberg et al. 2004, Oltedal et al. 2004). Fear is often connected to feelings of uncontrollability which is why fear can be associated with pessimistic risk evaluations or judgement. Therefore, an individual believes he or she could have a degree of control over a situation,

for example through taking hygiene measures to keep them safe, then it could provide a plausible explanation as to why there was little concern over the risk of acquiring *C.difficile*. This view could also be connected to the perceived level of controllability as those in the outbreak area believed that their own infection prevention and control practice was the reason that they do not have many cases of *C.difficile*. This explanation would fit the risk perception literature whereby the more control someone perceives themselves to have over a risk, the less concerning it is believed to be (Schmidt 2004).

Notions of vulnerability were also particularly significant for the HCP participants. However, their perceived vulnerability differed in context to that of the public in that they were more concerned about the consequences towards them resulting from patients acquiring *C.difficile* while in their care. This included how they believed it could potentially impact on their professional identity and reputation. Although these concerns were voiced by HCPs in both geographical areas, this was particularly notable in the outbreak area. They held the belief that there was a fundamental lack of support and understanding within their organisation in relation to the challenges they faced, such as the day-to-day management of patients with *C.difficile* and the provision of training and resources. Furthermore, they believe that they were personally blamed by patients and their families when patients acquired *C.difficile*. As a result, there was a strong sense of feeling devalued and were no longer respected as caring, compassionate nurses. Healthcare professionals also strongly emphasised that continued criticisms about their care and competence in

media coverage about *C.difficile*, which they argue is often inaccurate and scaremongering, highly influences the way in which they believed they are perceived by others.

These findings are of particular importance as these perceptions can have a significant impact on staff engagement. Staff engagement, according to Cornwell (2014) is a broad concept that includes job satisfaction, staff feeling committed, management listening and involving staff and staff engaging with each other and the organisation for which they work. While there is no literature to draw up specifically related to this issue in relation to *C.difficile*, Cornwell (2014) reported a link between staff satisfaction and healthcare associated infections in general. This report was based on a study by Boorman (2009) who found a link between staff health and well-being and meticillin-resistant *Staphylococcus aureus* (MRSA) infection rates. The report also highlighted qualitative data about concerns raised by front line staff about the lack of commitment and engagement by managers, and at senior level in relation to healthcare associated infections. However, it is noted that there is insufficient detail of how this finding was established in order to appraise its robustness. On a similar thread, Maben et al. (2012) explored the links between staff experience of work and acutely ill older people's experiences of hospital care. They found that in clinical places where there were poor work climates, poor leadership and staff well-being was low, patient experience was also poor. Although this current study did not evaluate the direct relationship between staff well-being and patient experiences in the way that Maben et al.

(2012) did, the perceived vulnerability of the HCP and public participants strongly suggest that this has important implications in relation to the safe care and management of patients with *C.difficile*.

Acknowledging this level of vulnerability, and the relationship between well-being of staff and patient's well-being, significant attempts have been made in order to address this in England. The King's Fund Point of Care programme undertook an evaluation of Schwartz Center Rounds from a pilot conducted in 2009. These Rounds developed in the United States, provide a forum for multi-disciplinary HCPs to meet on a regular basis in a safe and confidential environment so that they can explore issues that have occurred at work while caring for patients. With the help from a skilled facilitator, specific scenarios, situations, or case studies are presented and discussed so that HCPs can talk about their involvement, share their perceptions, and experiences, reflect on challenges and difficulties and explain how they felt (Goodrich 2011). An evaluation of the pilot showed that HCPs found the Rounds significantly benefited them in terms of encouraging compassion, increasing empathy and understanding, and hearing and validating the concerns they had. They also reported that from a team perspective they encouraged networking, and strengthened multi-disciplinary working. Furthermore, Goodrich (2012) reported that while small, these Rounds brought about significant improvements to the hospital culture. As a result of this successful pilot, Schwartz Rounds have now been supported and implemented within other

healthcare organisations in England, with similar positive responses (Foster 2015).

Attribution of responsibility

The relationship between responsibility and blame and risk perception can be traced back to Cultural Theory as discussed in Chapter Two. Douglas and Wildavsky (1982) pointed out that the danger belief of a risk is an indirect way of apportioning blame. Douglas (1992) further ascertained that within the globalising society, risk had become part of the 'politicized' blaming system. In other words, responsibility and blame is an inherent part of risk. It is about having the right to know what went wrong, who was to blame and seeking justice for those likely to have been affected by the risk. As a risk is associated with uncertainty, the way in which risks are managed and controlled can often result in further conflict.

Today, a similar perspective can be seen in that, for many health-related risk situations and experiences, people seem to have become accustomed to assuming the worst and suspecting cover-ups which inherently generates demands for the attribution of blame and accountability (Durodie 2005). A fundamental element of risk perception research often explores how individuals seek explanations for why a particular event or situation has occurred. In doing this, they frequently allocate a level of responsibility to a particular person, a group of people or a specific organisation for causing the

event or situation and whether or not action was taken to prevent it occurring (Eiser 2004).

Threaded throughout most public focus groups were strong accusations of apportioning responsibility and blame in terms of who and what participants believed was responsible for the acquisition and spread of *C.difficile*. This included government officials for enforcing cutbacks, particularly around the cleaning, healthcare organisations for not taking responsibility for ensuring hospitals were kept clean and failing to listen to the concerns of nursing staff, healthcare managers for not implementing or reinforcing policy requirements or supporting ward staff, and nurses and doctors for poor attitudes and poor infection prevention and control practice.

What also appeared to be of particular significance with the distribution of blame or responsibility was in relation to whom this distribution was directed. One of the main groups of people that appeared to be frequently criticised, particularly by the public, were those that were perceived to have some degree of authority. For example, at ward level, they believed that poor standards of cleanliness was a major cause of the occurrence and spread of *C.difficile*, and for this they blamed doctors and nurses for the lack of cleaning they do and preventing cleaners from doing their job effectively. Thus, they appeared to be particularly protective over the cleaners, who they believed had little authority within the healthcare setting. In order to account for such perceptions, media

coverage, past direct experiences, and experiences that had been learned from friends and family were drawn upon.

This concurs with the wider risk perception literature whereby when a risk occurs which is potentially harmful to others, people immediately look to seek out who is to blame, and risk then often “*becomes a stick for beating authority*” Abraham (2009, p. 605). A plausible explanation for this could be that people generally rely on those in authority to be able to effectively manage risks and therefore to keep others safe. Thus, when this does not happen, these are the people that are called to account.

According to the wider theoretical risk perception literature, most discussions around health-related risks involve the attribution of blame (Eiser 2004, Zinn 2006). It is believed that uncertain or unpredictable adverse risk events are unsettling because they are unfamiliar and also threaten our sense of control (Schmidt 2004). Thus, assigning responsibility onto someone or something becomes a way of making sense of a situation, and ultimately provides a way of coping with this lack of familiarity and control (Coxhead and Rhodes 2006, Haggett 2010, Ankomah et al. 2011). Alternatively, apportioning responsibility and blame can be used as a risk avoidance strategy, whereby the person then absolves themselves from taking any action (Hood 2013).

Despite this, the exploration into *how* risk perceptions can be influenced by the notion of blame appears to be largely unexplored empirically. However, a

study by Dixon-Woods et al. (2009) offers some insight. Healthcare associated infections in general are rarely associated with what Dixon-Woods and colleagues refer to as “*tightly coupled errors*”, in the sense that the occurrence of infection is not an immediate visual outcome of poor practice (Dixon-Woods et al. 2009, p.363). As a result, the acquisition of an infection, or even an outbreak, cannot easily be traced to any one individual or any specific set of actions or inactions. This inevitably delayed feedback between practice and consequence is recognised as specifically challenging in relation to healthcare-associated infection risks (Storr et al. 2013). For this reason, responsibility is often widely diffused and blame is therefore easily spread. While individuals may continue to complain about certain others, practices and processes, perceived human and organisational errors will often relate to issues of interdependence which make individuals feel disempowered (Dixon-Woods et al. 2009). This then allows for the externalisation of blame because the causes of the problems are a consequence of deficiencies beyond the individual. In this sense, such perceived errors are often normalised by simply accepting things as they are as individuals feel they have little or no control over change (Rickard 2014). Hood (2013) argues that this is an important element of the ‘blame game’- a term widely used in policy debate. It is seen as a blame avoidance strategy whereby the interaction between the blamer and the blamed combine or conflict to seek to pass the blame onto others. However, such a strategy has the potential to undermine intra-network co-ordination and team work, and thus places a threat to the effectiveness of implementation of risk-related policies (Hood 2002).

This pocket of theoretical and empirical literature highlights that the relationship between blame and risk aligns with the way in which the focus group participants of this study frequently apportioned blame and responsibility for the acquisition of *C.difficile*. These focus group findings therefore, seem to indicate that despite recognition that a blame culture prevents engagement in improvement and stifles innovation within healthcare organisations (O'Neil 2013), it still exists. This therefore has important implications for individuals who manage and communicate about *C.difficile* risks to both HCPs, and the public if the apportion of responsibility and blame is to be prevented or counteracted.

Making sense of competence

While the participants appeared to frequently apportion blame onto others, this contrasts with findings in Dixon-Woods et al. (2009). On studying how HCPs and colleagues classified and accounted for risk in medical wards, Dixon-Woods et al. (2009) found that some HCPs frequently admitted to not adhering to good practice all of the time, often due to influences beyond their control, such as heavy workload. However, this current study found that both HCP and public participants believed that they always acted appropriately and in a competent way, even though they believed others did not owing to external influences. The distribution of blame to others, therefore seemed to act as a platform to reinforce their own personal and professional competence, particularly in spite of competing demands and challenges.

An example of this was illustrated in Chapter Six when a patient with *C.difficile* was transferred to a healthcare setting. The deputy manager (Derek) explained in the focus group that the nursing staff in the ward had little knowledge of *C.difficile* or experience of managing patients with *C.difficile*, and received very little help or support externally. Yet despite this, he explained that they took matters into their own hands and ensured they educated themselves to an appropriate level. As a result, they were satisfied that they had gained the knowledge and skills to care for the patient appropriately and safely, and therefore were not concerned about spreading *C.difficile* to other patients, visitors or staff in the ward.

From this scenario, it could be argued that the perceived benefits of taking such action themselves, despite the lack of external support, were of significance. For example, the HCP participants expressed the concerns they had about the potential spread of *C.difficile* and understood the harm it could cause. Moreover, they explained that the patient's family were initially extremely anxious and angry due to way in which they had been dealt with by the transferring hospital. Thus by ensuring they had a competent workforce within the ward, they would gain the families trust and acceptance as well as ensuring their other patients was not harmed through the spread of *C.difficile*. This is supported within the HBM within both the perceived benefits and self-efficacy components as discussed in Chapter Two. For example, the more someone believes that taking a specific course of action will result in a positive outcome, the more likely they are to do it. Additionally, if they have faith or

belief in themselves around their ability to take appropriate action, then they are likely they are to do it (Duran 2011, Beer et al. 2012).

Reflecting on Dixon-Woods et al's (2009) study, however, further insight can be gained. There were some HCPs who did present themselves as competent practitioners, yet when in clinical practice their self-perceived competence was not confirmed through observation. Such disparity of perceived self-competence in healthcare and actual observed competence is well documented within the literature (Burnett et al. 2008, Edwards et al. 2012, Jackson et al. 2014). Although the purpose of this current study was not to establish actual competence of practice, the fact that all focus group participants were keen to present themselves as competent in infection prevention and control practice must be considered alongside with the wider literature. This affords invaluable insights around self-perceived competence and actual competence, which must be considered carefully when managing and communicating about *C.difficile* due to the implications for patient safety.

Perceived self-competence was also illustrated through the way certain elements of healthcare had changed over the years, which was believed not to be for the better. For example, an unwelcome 'change to the norm' noted by HCPs was the way in which nurses of today were trained. On making comparisons to the 'old style' of nurses, the 'new nurses' were seen as inadequately trained, 'not interested in being a nurse', and only there to 'gain a degree or diploma'. Additionally, the 'old style' nurses viewed themselves

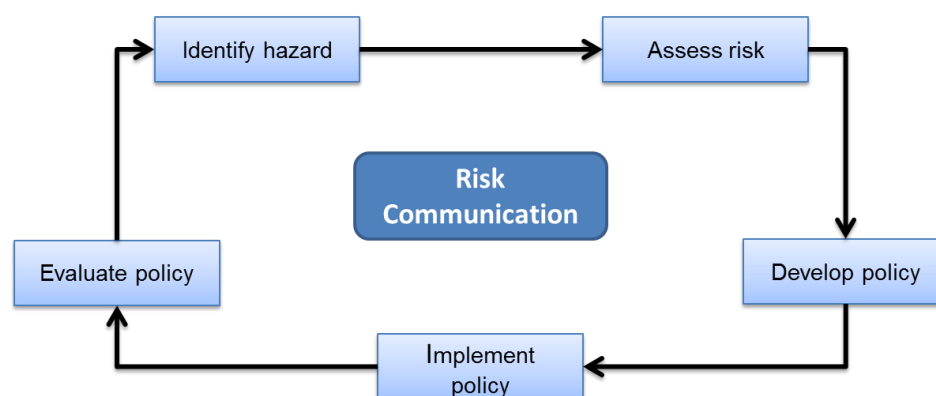
are more caring and patient focused. Consequently, HCPs believed that by the time student nurses of today qualify, they lack the knowledge and skills to be able to manage complex healthcare issues such as *C.difficile*. Such perceptions need to be considered carefully by risk managers and communicators as pointed out by Harrod et al. (2013) because any changes to the norm within healthcare can often be seen as threatening. As individuals have to make informed choices as to where their alliances lie when changes occur, it can have a significant impact on behaviour and attitudes towards a health-related risk, and in particular individuals who they are associated with.

Although, not directly related to risk perceptions, Milligan (2003) suggests that the nostalgia is often used by groups of individuals to create and build generations, and construct identities through their shared experiences. Contextualising this within nursing and healthcare, Gillett (2014) further adds that through the construction of such group identity, nostalgia allows those who were educated 'old style' to view themselves as more caring, and to distance themselves from newcomers who lack those shared experiences and values. Others argue that these discourses of nostalgia can therefore be mobilised as devices of resistance within healthcare (Tsouroufli et al. 2011). This has important implications for risk managers and communicators if behaviour and attitude change towards needs to be achieved.

Evaluations of the communicators

Given that people can only construct perceptions about, and respond to a risk if they possess some degree of information about it, effective and appropriate risk communication is therefore considered to be critical (Breakwell 2001, Casino 2010). According to Aakko (2004), risk communication about a health-related risk should be an open, honest interactive and continual process in which audience members are active participants so that the complexities of fear, anxiety, mistrust and uncertainty can be addressed in the most effective way. Beecher et al. (2005) further add that, if adequately applied, risk communication strategies can help people with differing perspective and levels of expertise to share a common and accurate understanding of and response to a risk. Risk communication is therefore considered the core challenge and an inseparable part of the wider process of risk management (Figure 9) (Health Protection Network 2008).

Figure 9: Risk management and risk communication



Despite this, Infanti et al. (2013) point out that due to the complexity of how people judge and evaluate risks, risk communication strategies are often found to be problematic. For example, they often fail to reach intended communities; can be ineffective at building trust; do not always acknowledge uncertainty; and fail to take account of their audiences' diverse perceptions of risks. As a result, rather than addressing important risk-related issues, risk communication strategies have the potential to magnify fear and uncertainty, increase distrust, and can act as a fundamental barrier to the adoption of appropriate preventative actions, and may even increase the health risk (O'Neil et al. 2007, Cole and Fellows 2008).

The public participants' judgements about expert risk communicators were expressed frequently and spontaneously, and were largely less than favourable. This was more noticeable for those in the outbreak area than the non-outbreak area. Many believed that, overall, there was a general lack of information about *C.difficile* available to them. Some believed that not providing information was actually a deliberate attempt to hide the experts own lack of knowledge and to prevent the public and patients from asking further questions. Some also expressed concerns about contradictory information being provided, which seemed to further enhance the suspicion of hidden agendas and lack of expert knowledge. As a result, many were distrusting of the information provided, and it was therefore often dismissed as inaccurate and irrelevant.

The link between risk communication, distrust and risk perceptions is well documented (Bellaby 2003, Frewer 2004, Gilk et al. 2004, Chryssochoidis et al. 2009, Engdahl and Lidskog 2012, Fang et al. 2012, Gesser-Edelsburg et al. 2014). When individuals are uncertain about a risk, they have to place trust in others to provide them with the appropriate information and guidance as to what action they need to take in order to stay protected. The reliance is therefore placed on individuals' own judgement about whom or what to trust. Not surprisingly, when risk managers and communicators are deemed to be knowledgeable they are more likely to be trusted and to be seen as credible, therefore the information they provide is likely to be accepted and acted upon (Frewer 2004, Perko et al. 2014). Similarly if experts are believed to lack knowledge and understanding, they are likely to be viewed as less trustworthy, thus information they provide is likely to be ineffective (Ferguson et al. 2009). Moreover, the guidance provided by distrusted sources may be discounted and have the opposite effect from what was intended (Johnson and White 2010). Such claims support the findings of this study.

Another significant factor which seemed to influence whether or not an expert was believed to be competent and knowledgeable and therefore trusted, related to the physical appearance of 'professionalism'. For example, public participants appeared to accept and respond favourably to risk information from an individual who they believed looked 'professional'. The relationship between trust of health-risk experts and the visual appearance of professionalism seems to be less explored specifically in risk perception

literature, although other wider health-related studies exploring its impact on trust have illuminated this finding (Skorupski and Rea 2006, Albert et al. 2008, Wiggins et al. 2009).

It is suggested that risk communication by experts needs to build trust while deploying an interactive process between the risk communicator and the recipient with a goal being to reduce fear and anxiety (Aakko 2004). Others however, have argued that feelings of fear and anxiety around risk are not necessarily a negative thing as they can drive people to listen to risk messages and take advised precautionary measures (de Hoog et al. 2008, Li et al. 2014). It is accepted that there is a fine line between having an acceptable level of fear and inducing panic (Sandman 2003). To some degree this aligns with other literature whereby negative or 'risky' messages about a hazard have more of an impact on acceptance and trust of risk messages and on risk perceptions, than positive or beneficial risk messages (Baumeister et al. 2001, Siegrist and Cvetkovich 2001). Rodriguez and Lee (2010) argue that messages that do not over-reassure people or convince them that there is nothing to be afraid of are likely to be accounted for as suspicious in that information is perhaps being withheld. In other words, acknowledging uncertainty and risky issues indicates honesty and transparency of the risk communicator.

In addition to experts, this study demonstrated that the media are also key health-related risk communicators. Media coverage of *C.difficile* and indeed

wider health-related risk issues, mainly from newspapers, were often used by both the public and HCPs in order to support or refute claims being made and to authenticate their accounts. As a result, they appeared to repeatedly move in and out of acceptance of stories, depending on whether these supported or challenged their own perceptions, preconceptions and/or experiences. Yet despite this, there seemed to be a marked distrust of the media and participants were often quick to assert that they (as opposed, presumably, to the more gullible, 'others') did not believe what was written in newspapers. Additionally, they accused journalists of twisting facts and not telling the whole truth in an attempt to sell more newspapers.

Although the media are only one part of a range of health risk communication sources, given that they have the power to disseminate risk information to a global audience very quickly, undoubtedly they play an important role in shaping risk perceptions and guiding responses (Kitzinger and Davidson 2001, May 2005, Kitzinger 2009, Reynolds 2011, Sandell et al. 2013, Cairns et al. 2013). However, others go further and argue that due to dramatic and sensationalist media coverage, the media often cause heightened fear and irrational risk perceptions (Jackson et al. 2006, McLaughlin et al. 2008, Washer and Joffe 2006, Washer et al. 2008, McCluskey and Swinnen 2011). Holtz (2010) further suggested that the way in which newspaper stories shape and influence how individuals view and respond to the world beyond their direct experiences, is often by how closely someone relates to the story rather than how verifiable it may be.

However, others argue that while it would seem untenable to suggest that the media does not directly influence their audiences, such suggestions are unfair and unsupported (Baillie 1996). Boholm (2009) alluded to this and pointed out that "*there is no simple transfer of media content to an audience, but rather a complicated interaction*" (Boholm 2009, p.1576).

To demonstrate this, a recent study by Pachur et al. (2012) examined how people judged risks through heuristics. They found little evidence to suggest that availability of instances learned by media representation impacted on risk perceptions once direct and indirect experiences were taken into account. On a similar thread, another study by Kpanake et al. (2008) compared societal risk perceptions of a group of villagers without access to the media (mainly newspapers, television and the internet) with another group of villagers who did have access to the media. They found that there were few differences in risk perceptions between both groups and concluded that, while there is some indication that the media do have a part to play in shaping risk perceptions, the overall impact of the media is not as strong as the literature perhaps suggests. However, within the study, it is noted that the amount and content of the information about societal risks provided to these two groups of people through different sources such as health information from health services other than the media, makes it impossible to exclusively disentangle media coverage from other sources.

By way of contrast, Sjoberg and Engelberg (2010) reported to have found some degree of media impact on risk perceptions in their study. They examined the impact of entertainment movies on risk perceptions and found that there was evidence to suggest that there were either enhanced or diminished risk perceptions immediately after watching the movies, although they did fade after a period of time. The authors put forward a number of factors which could explain these findings. First, the discourses that the media uses appears to be important. For example, the use of negative connotations as opposed to more positive ones appears to be key to the way in which messages are interpreted. Second, the level of knowledge about the topic prior to media representation could influence how a person makes sense of it. For example, the more knowledge a person has, the more rational judgements of the media coverage will be made. Third, the level of social interaction a person may have can also have an impact. For example, how much the topic is talked about among a person's social group and in what way can influence how they may perceive it.

The above studies and this current study therefore contradict strong assumptions that media coverage are largely responsible for causing enhanced fear and irrational risk perceptions. Undoubtedly, the media certainly play an important role in shaping risk perceptions and responses, but it is clearly evident that the interplay between the media and their audience is a complex one, and that the audience are not simply passive recipients. Sjoberg and Engelberg (2010) believe that media representation about an

already known risk may simply act as a reminder of the risk rather than adding to the perceptions because it is already stored in memory. This current study also adds, which is supported by Philo (1999), that audiences will choose to accept or reject media representations of risk depending on a variety of subjective factors, some of which are detailed within the conceptual framework of risk perceptions that emerged from the findings of this current study. For example, within the 'being vulnerable' component of the framework, many HCP participants spoke about how they believed the media were only interested in when they made mistakes and things went wrong, and drew upon specific media representation as if to attempt to strengthen or validate their claims. Similarly, for the public participants, they often shared with each other their perceptions of poor nursing care and bad attitudes of HCPs and discussed specific personal testimonies they had read about in newspapers, again as a possible attempt to strengthen and validate their perceptions.

Finally, Lacey (2002) points out that it must not be forgotten that media audiences are also 'providers' as well as 'consumers' of media content. For example, people want to see their own social groups represented in the media and to be able to communicate through the media. Thus, the media will inevitably attempt to respond to what they believe their 'consumers' are seeking from them.

From a media production perspective, in order to connect with their readers as well as imparting 'the news', the journalist and editor participants in this study

highlighted the importance of locating a story 'hook' so that characters and identities could be created and re-created. A popular strategy for achieving this according to Henderson (1999) is through the use of historical analogies. Such analogies allow journalists to link past situations or events with the current ones, thus helping readers to understand and interpret the story by encouragement through the recollection of other similar events. This was noted in the media coverage analysis whereby reference was made to a completely unconnected highly publicised *C.difficile* outbreak which had occurred previously in another country, but had catastrophic consequences. Kitzinger (2000) adds that these 'media templates' have a shelf life in which they extend beyond current news, insomuch that they are a point of reference used to explain current events, often as proof of an on-going problem. Embedded within these templates therefore are familiar patterns of specific risk issues.

It is perhaps for this reason that media coverage of health risk events such as a *C.difficile* outbreak often reveals patterns in the assignment of blame. Petts (2001) and Kitzinger (2008) explain that when adverse events occur, particularly in health related risk issues, there is often wrong-doing attached to them. As a result, media professionals believe that it is their job to reveal to their readers what has gone wrong and who was responsible. An effective way of doing this is through emotive accounts. The media coverage analysis in this study supported this as a number of particularly emotive personal testimonies from the *C.difficile* outbreak were published throughout all

newspapers. Moreover, it was the personal testimonies that were singled out by many participants in order to support their views. This suggests that emotional and moral appeals within health-related risk stories have greater salience than either managerial or political appeals in terms of shaping public and professional responses to *C.difficile*.

However, despite this 'story-telling' approach, the media participants' in this study strongly refuted criticisms that they purposively attempt to twist facts or produce inaccurate accounts. Rather, they were keen to reinforce that their job is simply to tell the public what is going on in a way that was simple and easily understood. Indeed, they seemed to be fiercely protective of their own professionalism, taking great pride in ensuring they are known as credible journalists or editors.

One of the reasons why the media participants stated they believed they were so highly criticised by health experts and researchers is a limited understanding of their role, and of the barriers and constraints that they face. Such a view is supported by others (Kitzinger 2009, McCluskey and Swinnen 2011, Hooker et al. 2012). For example, in order to report accurate accounts in risk stories, media participants reinforced the need to be able to locate and converse with the best possible sources within the often very tight time scales that are required. Such issues can, therefore, have significant impact on the accuracy, balance and the proportionality of risk stories in the media, which must be acknowledged (Ashe 2013).

All of these issues bring to light the complexity of risk reporting in the media. Although it acknowledges frustrations from scientists and researchers perspectives, it offers some explanations as to what gets produced in the media and how and why it gets produced. Such understanding can be used to bridge the public-expert-media divide and help identify ways of working together in order to provide a balanced level of health risk reporting. Additionally, it can allow risk communicators to pre-determine what is likely to be reported about health-related risk events, and develop strategies so that potential confusion and fear arising from media coverage can be attempted to be counteracted.

Study contribution

Some key findings have emerged from this study. The emergence of a structured conceptual framework of risk perceptions from the focus groups as illustrated schematically at the beginning of this chapter, provides a generic account of the way in which people construct and communicate about risks. This is then fleshed out in the detailed context of *C.difficile* through underpinning themes. This enables a comprehensive, generic and context specific understanding of risk perceptions, further adding to current theory. It resonates with assumptions that the public perceive risks subjectively, based on the influences of the social world around them, which ultimately impacts on the way in which they respond to risk. With regards to 'experts' however, this study calls into question earlier theoretical assumptions, which continue to

inform research today, that expert risk perceptions are formed objectively through the integration of scientific information. Findings suggest that this is not the case and those 'expert' risk perceptions, are formed in very similar ways to that of the public.

This study suggests that people are more concerned about the consequences of the perceived risks surrounding *C.difficile* to themselves (both at an individual and professional level), rather than the perceived chances of it occurring. It highlights the importance of considering the perceived vulnerability of individuals within the context in which they occur, and the diverse range of factors or characteristics that are of significance.

This study demonstrates that risk issues which were perceived to be related to *C.difficile* were not only talked about directly and explicitly, but also indirectly and implicitly in rhetorical and social ways, such as in the use of imagery and language. In doing so, previous experiences and perceptions were often contextualised. By acknowledging the ways in which individuals seek out and use health-risk information, the media uses this to appeal to their readers by creating emotive and memorable stories. However, the relationship between the public and healthcare professions and the media is a complex, ambivalent and contingent one. On the one hand, individuals use the media to quickly access information which is easy to understand and interpret, yet on the other hand, there is a fundamental distrust of the information that the media provide. Despite this, individuals frequently move in and out of acceptance of health-

related risk stories depending on whether or not the stories align with or refute their beliefs.

This study also moved beyond the standard critique of media output and unsupported assumptions of media influence and demonstrated that the relationship between the public and healthcare professionals and the media is complex. The findings show that the media plays a crucial role in influencing how individuals perceive and respond to risk, but emphasises that this is largely dependent on already formed perceptions and social influences. This sets out challenges for risk communicators in relation to considering how to use media coverage as an integral part of risk communicating and management strategies.

Finally, the multiple accounts elicited within this study enabled the capture of in-depth insights into explanations and construction of risk perceptions. This study is the first study of *C.difficile* to develop an understanding of specific risk factors that are important to these groups and which impact on how they respond, both physically and emotionally. The findings of this study therefore can be invaluable to the future management and communication of not only *C.difficile*, but also other healthcare-related risks.

Implications for practice

As identified in the literature review, there are limited frameworks to draw upon in order to understand risk perceptions and responses for healthcare-related risks. The conceptual framework developed from the findings of this study can help those responsible for managing and communicating risks around *C.difficile*. For example, the framework demonstrates that past experiences of healthcare, regardless of whether or not they relate directly to *C.difficile*, can have a significant impact on how people think about *C.difficile*. Additionally, how social contacts, such as friends, family and colleagues, think about and react to issues relating to *C.difficile* can have a direct influence how people close to them then think about it. Such subjective influences need to be considered carefully and taken into account when managing risks and communicating about risks relating to *C.difficile* and indeed wider health-related risks.

Participants in this study stated that their knowledge and understanding about various aspects of *C.difficile* was limited. A person's capacity to obtain appropriate information, make sense of it, and retain it in a way that will encourage them to respond in a safe and coherent manner, is vital for effective prevention and management of *C.difficile*. Those responsible for communicating about *C.difficile* must therefore do it in a way that facilitates this process in the easiest way possible. This should not be considered in a 'one size fits all' context. Rather the need is for the provision of *meaningful* information about *C.difficile* for the public and HCPs, rather than simply *more*

information. Information provided must address individuals' needs and take into consideration already formed risk perceptions and past direct and indirect experience. Additionally, consideration must be given to other information people may have been exposed to and the impact this may have had, particularly from the media.

Ensuring protected and uninterrupted time to communicate about *C.difficile* in a meaningful way with patients and their families is vital. This could be achieved by ensuring adequate protected time is set aside to allow for engaged dialogue. For instance, if the communicator only has a small window of time available, the discussion could be re-arranged for when there is more time available. Having an allocated 'quiet room' with appropriate signage on the door to prevent interruptions would also be conducive to an in-depth discussion. Additionally, patients should also always be given the opportunity to include members of their family or friends in any discussion. Finally, individuals should always know the name of the HCP with whom they are having the dialogue and be reassured that they can be contacted to return at a later day/time if required.

This study demonstrated that using a single method of providing information about *C.difficile*, such as the use of patient information leaflets or the distribution of policies, is likely to be ineffective. When communicating about *C.difficile* with both the public and HCPs, consideration must be given to using a range of methods, both verbally and written and pictorial. For example, this

study has shown that patient stories and people's direct experiences are particularly powerful for engaging others about risk issues. If healthcare organisations used such stories in conjunction with more formal guidance of best practice, it will likely have a much greater impact than using guidance alone.

Having trust in the HCPs who are responsible for managing and communicating about *C.difficile* was seen as very important to the public participants. Healthcare organisations must ensure that HCPs are skilled communicators so that they are able to build trusting relationships which will encourage others to express their perceptions and concerns freely without fear of being dismissed or ignored. Equally, it is important that HCPs are prepared as much as possible to respond openly and honestly to potential questions and concerns patients and their families may express. This could be achieved through the use of real-life scenarios and role play between multi-disciplinary healthcare professionals in a clinical skills centre or another safe learning environment. Staff can then be given the opportunity to reflect and work together to seek ways in which their skills can be enhanced. This may include learning to introduce themselves appropriately, being able to listen, watching for cues through verbal and non-verbal language, being inquisitive and asking open-ended questions.

The HCPs in this study largely believed they are often blamed for patients acquiring *C.difficile* and often do not feel valued or supported. There is a need

for healthcare organisations to respond to the needs of HCPs by ensuring that a person-centred culture is fostered so that they feel valued and supported at all times. This could be achieved through the measurement of staff experience in order to understand and address important factors. Additionally, healthcare organisations could consider the development and implementation of Schwartz-type Rounds as discussed earlier so that HCPs have the opportunity to come together in a safe and confidential environment to reflect on emotional aspects of their work which can lead to enhancing the organisational culture and therefore have a positive impact on individuals, teams, patient outcomes.

Better understanding of the role of the media in terms of reporting about *C.difficile* is required. Given that the media are important in shaping risk perceptions and responses to some degree, dismissing coverage as sensationalist and inaccurate is likely to be counterproductive. Understanding how the media is likely to report on future *C.difficile* outbreaks or incidents is critical to developing effective communication strategies. For example, messages can be tailored to address potential misconceptions reported in the media, and also answer specific questions the media are likely to present in their coverage. Moreover, the development of communication strategies should take place before negative news emerges when possible. Additionally, healthcare organisations need to be aware that the media rely on experts within the field to provide them with important information. If that information is not imparted to the media, then the media will find information from perhaps

less credible sources. Being more engaging, open and honest with the media may go some way to help prevent inaccurate or sensationalist reporting.

The impact of communication strategies developed for *C.difficile* should be continually monitored and evaluated so that any negative effects can be identified and improvements made.

It must be accepted that the risks individuals associate with *C.difficile* and how they respond to them are not certain or fixed, and can change frequently depending on experiences, events and social influences. Communication about *C.difficile* therefore cannot be considered a one-off activity. Innovative communication strategies must be developed to ensure information is available, easily accessible and interpreted and communicated in a variety of ways on a continual basis. Additionally, messages must also continually evolve to address context specific and situational factors. One way of achieving this could be in the form of public engagement seminars or workshops within wider communities using presentations, posters, videos and/or question and answer sessions. This would also reassure the public that their views and opinions are taken seriously.

Implications for education

This study has provided an understanding of how the public and HCPs form and modify perceptions, and make sense of risk issues they associate with

C.difficile. As this understanding has not been established until now, these findings have many implications for education around *C.difficile*, other healthcare associated infections and healthcare-related risk issues. The conceptual framework of risk perceptions developed from this study can be used to design and develop education within the undergraduate and post graduate nursing programmes.

The importance of understanding risk perceptions of the public, patients and HCPs needs to be embedded within the undergraduate and postgraduate curriculum so that students and HCPs are able to respond effectively within clinical practice. Using specific dialogues from the participants of this study in undergraduate and postgraduate education can help students and HCPs understand the complexity of how and why risk perceptions and responses are shaped. Learning material can then be developed to help students identify ways in which they can effectively manage *C.difficile* and communicate with patients, families and other HCPs about *C.difficile*. For example, the media coverage analysis can be used to allow students to understand what information patients and their families may have been exposed, which could then offer explanations as to why they may be anxious, fearful or angry. The conceptual framework of risk perceptions and corresponding dialogue from participants could be used to demonstrate important factors that students and HCPs need to understand within clinical practice that contribute to ensuring that a person-centeredness approach is achieved.

Using some of the public and HCPs perceptions and experiences can be developed into specific scenarios for communication training which can be videoed or audio-taped, then used for feedback and reflection.

This study has also been effective in a number of ways within a post graduate nursing programme. For example, within the MSc Infection: Prevention and Control programme, not surprisingly, media coverage of infections is a topic that arises frequently and generates a great deal of heated debate, criticising the media for inaccurate reporting and causing unnecessary fear. By using examples from the media coverage analysis and journalist interviews, it has allowed students to reconsider some of their pre-conceived ideas and perceptions, understand the role of the media, and think of ways in which they may engage more positively.

The findings of this study have also been used to influence the development of an international infection prevention and control educational programme, thus demonstrating how wide an impact this can have on education.

Directions for further research

As identified above, this study identified a paucity of frameworks available to help researchers understand how and why people perceive health-related risks. The use of this conceptual framework developed from the findings of this study, can provide a platform for researchers studying risk perceptions of other

health-related risks and enable them to build on it so that a more substantial framework for future risk perception research can be developed.

Data for this study were generated at specific points in time and revealed a range of important factors for understanding risk perceptions and responses around *C.difficile*. Therefore, it provided a snapshot of risk perceptions and responses at specific points in the trajectory of understanding. However, as it has been established, risk perceptions and responses to risk are not fixed and will alter over time, it would be fruitful to consider longitudinal studies, generating risk perception data over time, particularly during the occurrence of specific adverse events, such as when outbreaks occur. This will allow an understanding of what factors are particularly powerful in relation to modifying risk perceptions and responses over time during a significant event.

This research has clearly identified that the media has a significant role to play in shaping risk perceptions and response. There is an array of risk-related research that continues to make unsupported claims as to the impact of the media on risk perceptions, and the role of the media in health-related risk reporting. This study can therefore help inform future research to include media impact and the role of the media around other specific health-related risks.

It is recognised that print newspapers are only a small section of a wide range of media sources, such as television, radio, magazines, the internet, social

media platforms, blogs and software applications. As different groups of individuals are likely to access information from a variety of different sources depending on needs and applicability, future research should consider how these different sources may impact on risk perceptions.

Similarities and differences between the public and healthcare professionals were evident in this study. What is of significance is that commonalities included that HCPs risk perceptions and responses to *C.difficile* were influenced by very similar subjective factors to those of the public. The differences on the other hand were in relation to the context in which they were constructed. As the findings of this study have implications for practice, future risk perception research should consider including senior managers within healthcare organisation. This may allow for a more streamlined approach when developing management and communication strategies and encourage risk perception to become an integral part of risk decision-making.

A final personal reflection

During early thoughts about this PhD study, I was very clear about the topic of risk and *C.difficile*, but I needed to do lots of reading, thinking and writing before the proposal was refined enough to run with. It took a good part of a year to do this. My MSc dissertation was a quantitative study, yet I never really saw myself as a positivist thinker. I remember feeling very disconnected from my study and particularly from my participants. I didn't settle well not knowing who they were. Quite simply, I like to talk to people. I also remember looking frustratingly at my results and thinking, how? why? The numbers just didn't connect with me, I needed to know more. My first qualitative research study felt good and I relished the interaction I had with the participants while listening to their stories. This is why I knew for my PhD study, I wanted to gain diverse insights from diverse methods.

In my clinical role, I had years of experience caring for patients with *C.difficile* and supporting HCPs in the management of patients with *C.difficile*. As a result of this, I did have some preconceived ideas about what my public and HCP participants would say. Additionally, over the years, I admit to having gained a marked distrust and even a dislike of the media, which made me nervous about including them in my study. However, from my clinical experience and from what I had read in the literature, I knew they were an important inclusion.

While some of my preconceived ideas did come to fruition, by facing this study with an open mind, I learned more about the participants than I ever imagined

possible. The way in which they see the world, the things that are important to them and the way in which they live their lives actually makes me wish I could step back in time and do things very differently as an infection prevention and control specialist practitioner. I have been, and will continue, to use the findings of this study to make differences in other ways – through dissemination, future research, and education and through other wider opportunities that may come my way.

In terms of the PhD process, this has been an extraordinary experience. The data collection periods were without a doubt one of the most enjoyable and exciting parts for me. To have been accepted into the world of so many people, who talked so freely and in-depth about many personal and sometimes difficult aspects of their lives was extremely humbling. Despite my preconceived ideas about media professionals, conducting their interviews was enlightening, and at times, extremely funny. Many of the participants were certainly very colourful characters. However, there was also a very serious and vulnerable side that was clearly evident. My views about the media have changed and I have come to understand them rather than resent them.

Of course there were difficult and challenging parts. Admittedly, I least enjoyed the recruitment stages. It took much longer than I had anticipated and at times I often felt like a salesperson, which made me feel quite uncomfortable. Nevertheless, through sheer determination and with help and support from others, I got there in the end.

Throughout the course of this study, I had three sets of supervision teams. There were times where I struggled with competing views and different perspectives and I lacked confidence in my ability to make decisions. However, because of this, I believe I have developed into a more knowledgeable, skilful and confident researcher. I also feel extremely privileged having been guided and supported by such experienced and well respected researchers and supervisors. This I know has been instrumental in developing, progressing and ultimately completing this study. Additionally, it has taught me about the type of supervisor that I want to be in the future.

Undertaking this PhD study has been an amazing experience and one that has had a significant impact at both a personal and professional level. For that I will be eternally thankful.

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Appendix one: Methodological characteristics of included studies (patient and public)

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Abbate et al. (2008)	Patient's knowledge, attitudes and opinions towards hospital-associated infections	Descriptive, cross-sectional survey: Questionnaire	Inpatients from 3 different acute hospitals (450): Italy	Uncertainty; Perceived low probability of acquisition of infection; Information; Direct experience; Media representation	Did not speak up when experienced poor practice	Limited insight into why perceptions were what they were
Brinsley-Rainisch et al. (2007)	Public awareness, knowledge and perceptions of MRSA	Descriptive, cross-sectional: Focus groups	Members of the public (63: 8 focus groups): USA	Uncertainty; Perceived high probability of acquisition of infection; Media representation		Unspecified sampling strategy; Limited findings reported; Limited participant variables; Despite using focus groups, no discussion of social constructions of understanding; No impact on responses explored

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Burnett et al. (2010)	Compare <i>Staphylococcus aureus</i> infected and non-infected patient narratives	Descriptive, cross-sectional: Semi-structured interviews	Patients post discharge (16) and Inpatients (4) from an acute hospital: UK	Uncertainty; Fearful of consequences; Distrust towards healthcare staff; Little confidence in the NHS; Lack of information; Direct experience;	Negative emotions	Limited participant variables; Potential recall bias from patients post discharge; Unsupported assumptions of media impact
Collins et al. (2009)	Public perceptions of <i>C.difficile</i>	Descriptive, cross-sectional survey: Questionnaire	Vascular & general outpatients (98): UK	Uncertainty	Negative emotions	Small sample; Limited exploration of level of risk perceptions, influencing factors; Inappropriate assumptions of media impact

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Criddle et al. (2006)	Patient experience and understanding of MRSA	Qualitative phenomenological: Structured interviews	Patients colonised with MRSA (post discharge from an acute hospital) (14): UK	Uncertainty; Distrust towards healthcare staff; Exaggerated information provided; Media representation	Negative emotions; Stop family visiting	Limited participant variables; Potential recall bias as patients interviewed 6 months post discharge
Hamour et al. (2003)	Patient awareness and perceptions of MRSA	Descriptive, cross-sectional survey: Questionnaire	Surgical out-patients attending pre-admission clinic or flexible cystoscopy (113): UK	Perceived high probability of acquisition of infection; Trust towards healthcare staff; Media representation; Indirect experience	Negative emotions	No participant variables; Limited results reported; Unsupported links with media impact
Gill et al. (2006)	Patient & public knowledge & perceptions of MRSA	Descriptive, cross-sectional survey: Questionnaire	Patients & public in an A&E department in an acute hospital (50)	Knowledge; Low probability of acquisition of infection; Media representation;		Limited participant variables; Small sample Limited exploration of level of risk perceptions & influencing factors

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
McLaughlin et al. (2008)	Public knowledge & perception of MRSA	Descriptive, cross- sectional survey: Questionnaire	Members of the public in shopping centres & visitors to an acute hospital (545): UK	Knowledge; Perceived high probability of acquisition of infection; Distrust towards healthcare staff; Inappropriate information provision; Direct experience	Negative emotions	Limited participant variables; Unsupported links with media impact
Madeo et al. (2008)	Patients knowledge, awareness, attitudes and beliefs about healthcare associated infection	Descriptive, cross- sectional survey: Questionnaire	Patient in regional teaching hospital (110): UK	Uncertainty; Media representation		Unspecified sampling strategy; Small sample; Limited participant variables; Limited findings reported; Unsupported assumptions of media impact

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Mattner et al. (2006)	Public knowledge of multi-resistant bacteria	Descriptive, cross-sectional survey: Questionnaire	Members of the public at a main metro junction (224): Germany	Knowledge; Fearful of consequences; Direct & indirect experience;	Negative emotions	Small sample; Non-representative sample (high number of students and pupils due to time of data collection); Some assumptions not supported by findings
Merle et al. (2005)	Surgical patients' knowledge and opinions regarding nosocomial infections	Descriptive, cross-sectional survey: Structured interview	Surgical patients in a tertiary care teaching hospital (65): France	Uncertainty; Lack of information; Indirect experience	Would seek legal action	Unspecified sampling strategy; Limited participant variables; Limited findings reported

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Miller et al. (1989)	Patients' knowledge of nosocomial infections	Descriptive, cross-sectional survey: Questionnaire	Public (previous patients) (976): America	Knowledge; Uncertainty; Lack of information; Direct experience	Would pay more healthcare fees to prevent infection	Low response rate (24%); Limited participant variables; Limited exploration of level of risk perceptions & influencing factors; Limited findings reported
Moore et al. (2010)	Comparison of public perceptions of healthcare associated in Northern Ireland to those in UK and worldwide	Descriptive, cross-sectional survey: Online e-survey	Members of the public in Northern Ireland (104), Great Britain (75), Australia (4), Germany (1), India (2), Malaysia (3), New Zealand (1), Republic of Ireland (3), South Africa (1), USA (7)	Fearful of consequences; Media representation; Indirect experience	Negative emotions	Small and unrepresentative sample; Limited participant variables; Limited findings reported; Unsupported assumptions of media impact

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Newton et al. 2001	Patient's perceptions of MRSA	Descriptive, cross-sectional: Semi-structured interviews	Inpatients with MRSA in an acute hospital (19): UK	Knowledge; Uncertainty; Direct experience; Information	Negative emotions	Unspecified sampling strategy: Limited participant variables: Limited exploration of level of risk perceptions & influencing factors

Appendix two: Methodological characteristics of included studies (HCPs)

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Aroori et al (2009)	Determine awareness of <i>C.difficile</i> amongst healthcare professionals	Descriptive, cross-sectional survey: Questionnaire	132 professionals (18 consultants; 40 trainee doctors; 74 nurses): UK	Level of knowledge; Poor understanding of risk factors;		Limited explanation of sampling & recruitment strategy; Authors stated participants had good knowledge, but this was not the case; No variables collected on participants
Gill et al (2006)	Examine experience and understanding of MRSA of patients, public and healthcare professionals (<i>this review concerned only with healthcare professionals</i>)	Qualitative phenomenological: Structured interviews	100 NHS employees (25 doctors, 25 nurses, 25 domestics, 25 porters): UK	Low perception of risk to self; Level of knowledge; Information sources	Perception that all staff should be swabbed	Low response rate; Limited variables collected on participants; Unsupported assumptions made in discussion


Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Lines (2006)	Examine staff nurses perceptions about MRSA	Qualitative, descriptive, cross- sectional: Semi-structured interviews	10 senior staff nurses: UK	Low perception of risk; Level of knowledge; Controllability; Trust	Perception that all staff should be screened; Poor practice	Limited explanation of sampling strategy; Limited variables collected on participants; Limited exploration as to why participants responded the way they did
Morrow et al (2011)	Determine whether healthcare staff hold false perceptions about MRSA	Descriptive, cross- sectional survey: Questionnaire	97 healthcare workers from hospital (n= 44) and care home (n=53) setting: UK	Low perceptions of risk in own clinical area, but high in other areas; Level of knowledge; Uncertainty; Controllability	Negative emotions; Blame towards others' practices	Small sample; Limited variables collected on participants; Limited exploration as to why participants responded the way they did

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Paudyal et al (2008)	Explore infection control knowledge, attitude and practice among healthcare workers	Descriptive, cross-sectional survey: Questionnaire	324 healthcare workers (166 doctors, 158 nurses): Nepalese	High perceptions of risk to patients and themselves; Level of knowledge; Controllability;	Poor practice	Limited participant variables; Limited exploration as to why participants responded the way they did
Prieto et al (2005)	Explore healthcare professionals' perceptions, priorities and anxieties about infection control practice in relation to <i>C.difficile</i> and MRSA; to design and implement supportive intervention; to determine self-reported changes in practice	Longitudinal cohort: Interviews and observation	Healthcare assistants (5) and qualified nurses (13): UK	High perceptions of risk to patients, themselves and their families; Uncertainty; Confidence	Poor practice	Unspecified sampling strategy: Unclear of the association between those interviewed and those observed; No participant variables

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Rémi Kouabenan et al (2007)	Examine perceived risk of contamination by MRSA among healthcare personnel	Descriptive, cross-sectional survey: Questionnaire	185 healthcare personnel, University Hospital (27.2% nurses, 29.73% nurse aides, 29.73% ancillary staff, 5.4% physios', 5.4% physicians, 9.18% volunteer staff): France	High perception of risk to themselves; Controllability; Length of service; Direct experience	Good practice	Limited participant variables
Tigg et al (2008)	Explore knowledge of healthcare workers regarding MRSA	Cross-sectional audit, questionnaire	441 healthcare workers (203 nurses, 33 hotel service staff, 58 AHPs, 47 doctors, 76 unregistered nurses): UK	High risk perceptions; Level of knowledge; Uncertainty; Media; Length of service	Negative emotions	Limited participant variables; Limited exploration as to why participants responded the way they did

Author(s) and year	Purpose(s)	Design And method	Sample and setting	Main findings pertaining to risk perceptions		Limitations
				Influencing factors	Impact on responses	
Tsagkaraki et al (2009)	Explore healthcare professionals' knowledge and perceptions of <i>C.difficile</i>	Descriptive, cross-sectional survey: Questionnaire	142 Healthcare (63 doctors & 79 nurses): UK	High risk perceptions; Level of knowledge; Consequences; Uncertainty		Small sample; No response rate; No participant variables; Limited influencing factors reported
Vaughan et al (2006)	Examine infection control link professionals' knowledge of <i>C.difficile</i>	Qualitative cross-sectional: Interviews	20 infection control link professionals: UK	High perception of risk; Level of knowledge; Uncertainty	Poor practice	Small sample; No participant variables; Limited influencing factors reported
Wolf et al (2008)	Investigate nurses' perceptions of the risk and severity of antimicrobial resistance and MRSA	Mixed methods, cross-sectional: questionnaire and focus groups	42 nurses (6 focus groups): US	High perception of risk to themselves and patients; Knowledge; Information provision; Uncertainty	Good self-reported practice, however, findings dispute this	Limited participant variables; Limited influencing factors reported; Did not explore the interaction between participants

**Appendix three: Public focus group recruitment
poster**




***Clostridium difficile* (C.diff):**
What do you think about it?
Have your say.....

I am conducting a research study for my PhD at the University of Dundee, School of Nursing and Midwifery. Part of this study aims to explore what the public think about the infection *Clostridium difficile* (C.diff).

Share your opinions and experiences:
Take part in a focus group and receive light refreshments and £15

Focus group dates and venues (in your area) will be confirmed following recruitment of participants. Each focus group will consist of approximately 6 - 8 people.

If you are interested in participating,
please contact:
Emma Burnett
e.burnett@dundee.ac.uk
Tel: 01382 386876
Before -- -- 2010



Appendix four: Public participant information sheet

Participant Information Sheet Public Focus Groups

Understanding risk perceptions and responses of the public and media professionals: The case of *Clostridium difficile*

1. Invitation

I invite you to participate in a research project I am undertaking for my PhD at the University of Dundee, School of Nursing and Midwifery. However, before you decide whether or not you wish to participate, I'd like to explain a bit about the study therefore I am providing you with the following information. Please do not hesitate to ask any questions (I have provided my contact details at the end of this sheet). I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

2. What is the purpose of this study?

There have been a number of significant outbreaks of *Clostridium difficile* within the UK over the past few years and research shows that the acquisition of *Clostridium difficile* while in hospital is a major patient concern. The proposed research is about Healthcare Associated Infection, in particular *Clostridium difficile*. It will look at how *Clostridium difficile* has been represented in local and national newspapers; explore risk perceptions of the public and media professionals towards *Clostridium difficile* and look at how these risk perceptions vary. This study can help to identify gaps between scientific knowledge and public understanding and will make recommendations as to how communication and the provision of information can be improved

There are three parts to the study;

- An examination of original newspaper articles about *Clostridium difficile*.
- Face-to-face focus groups with members of the public to explore risk perceptions and responses towards *C. difficile*.
- Telephone interviews with media professionals such as newspaper journalists and editors.

3. Why have I been chosen?

Previous research studies have shown that members of the public gain the majority of their information about *Clostridium difficile* from the media and social contacts such as friends and family. I would therefore like to talk to people from all walks of life in an area where there has been an outbreak of *Clostridium difficile* and in an area where there has not been an outbreak.

4. Do I have to take part?

If you are interested in taking part, you should complete the short questionnaire included with this leaflet and send back to me in the stamped addressed envelope

provided. I will then contact you to notify you if you have been selected to take part in the study. Whether you decide to take part or not is entirely your choice. You are under no obligation. If you do decide to take part, you may withdraw at any time and without giving any reason. This decision will not affect you in any way.

5. What will happen to me if I take part?

If you agree to take part, you will be invited to participate in a discussion with approximately 8 other members of the public. I, as the researcher will act as the group 'moderator' by asking questions and facilitating further discussions. The aim of the focus groups is for me to learn more about your thoughts around *Clostridium difficile*. You will be notified of the venue for the focus group nearer the time, but you will not have to travel far. You will be provided with light refreshments and £15 as a thank you for participating. This has been funded by the Ethicon in partnership with the Infection Prevention Society (www.ips.co.uk). Focus groups will be audio taped to help me to analyse the discussions.

6. What happens when the research stops?

Once the research study has been completed, a report of the findings will be written up for my PhD thesis. If you wish, you may contact me at any time to discuss the findings. Findings may also be presented at conferences and be published in peer-reviewed journals. In all cases, the anonymity of all participants is guaranteed at all times.

7. What Are The Benefits of The Study?

Clostridium difficile is a very serious concern. By exploring public perceptions of *Clostridium difficile*, it will enable me to identify ways to provide acceptable and appropriate public health information and look at ways in which we can ensure that the public are well informed about the risks they face. This will ultimately help to increase public confidence, enhance the patient experience, improve communication and reduce anxiety.

8. Will I have to give any personal details?

No personal information other than age, gender and background will be collected.

9. Will my taking part in the study be kept confidential?

Should you consent to taking part in the research, you will be allocated with a study number which will be used for all of the data collection. Any computer saved data relating to this project will only be accessible to myself and my two supervisors at the university. It will also be kept on a password protected university computer in locked offices. All information obtained in the study, including audio tapes from the focus groups will be stored securely and destroyed once the study is completed. You will not be identified by name in any report.

10. Who is organising the research?

I am undertaking this study for my PhD within the University of Dundee, School of Nursing and Midwifery.

11. Who has reviewed the study?

The University of Dundee Research Ethics Committee has examined the proposal and has raised no objections from the point of view of ethics. It is a requirement that all research records are made available to monitors from the university whose role is

to check that research is properly conducted and the interests of those taking part are adequately protected.

12. Contact for further information.

If you have any questions about this study please don't hesitate to contact:

Emma Burnett
Lecturer & Researcher, Infection Prevention and Control
University of Dundee
School of Nursing and Midwifery
11 Airlie Place
Dundee, DD1 4HU
Tel: 01382 386876
e.burnett@dundee.ac.uk

Thank you for reading this information and considering participation in this study.

Appendix five: Public participant questionnaire

If you are interested in participating in this study, please take a few moments to complete this questionnaire and return to me using the stamped addressed envelope provided. This will provide me with a range of information to help me select participants for my focus groups. **All information will be kept completely confidential.**

Name:

Address:

Contact Telephone Number:

Email address:

How would you prefer me to contact you: Telephone or Email:

1. Age (please circle)

16-25 years 26-35 years 36-45 years 46-55 years 56-65 years

2. Gender (please circle)

Male

3. Race/Ethnicity (please circle)

White (British/Irish)

Black & Black British (Caribbean/African/Other)

Mixed (White & Black Caribbean/White & Black African/White & Asian/Other)

Asian or Asian British (Indian/Pakistani/Bangladeshi/Other)

4. Religion or Belief

Christian Buddhist Hindu Jewish Muslim Sikh None

5. **Marital status:** (please circle)

Married Divorced/Separated Widowed

6. **What is your highest level of education?** (i.e. School, further education, diploma, degree, MSc, PhD)

7. **Occupation**

8. **Income:** (please circle)

<£20,000 £21,000 - £35,000 £36,000-£55,000 £56,000-£70,000
>£71,000 rather not say

9. **Have you heard of *Clostridium difficile* (*C.diff*)?** (please circle)

Yes No

10. **Have you had any direct personal experience of *Clostridium difficile* (*C.diff*)?** (please circle)

Yes No

11. **Do you know of anyone who has had experience of *Clostridium difficile* (*C.diff*)?** (please circle)

Yes No

12. **Do you regularly attend the hospital as a patient?** (please circle)

Yes No

13. Have you had any hospital admissions in the last 12 months? If so, how many? (please circle)

Yes No If Yes, how many:

14. What newspapers do you read? (Local, regional and national)



Please indicate what days and times you would usually be available to participate in a focus group by ticking the relevant boxes.

Suggested Days	Suggested Times (Please circle)
Monday	Morning Afternoon Evening
Tuesday	Morning Afternoon Evening
Wednesday	Morning Afternoon Evening
Thursday	Morning Afternoon Evening
Friday	Morning Afternoon Evening
Saturday	Morning Afternoon Evening
Sunday	Morning Afternoon Evening

Please write below if there are any days that you would not be available (i.e. holidays)

.....

Thank you for taking the time to complete this questionnaire. Please return to me in the stamped address envelope provided and I will contact at the end of them month to let you know if you have been selected to participate in this study. Please do not hesitate to contact me at any time if you have any questions. My contact details are on the participant information leaflet. Please also encourage any friends or relatives to participate!

Regards, Emma

Appendix six: Healthcare professional participant information sheet

Participant Information Sheet Healthcare Professionals' Focus Groups

Understanding risk perceptions and responses of the public and media professionals: The case of *Clostridium difficile*

1. Invitation

I would like to invite you to take part in a research project I am undertaking for my PhD at the University of Dundee, School of Nursing and Midwifery. However, before you decide whether or not you wish to participate, I'd like to explain a bit about the study therefore I am providing you with the following information. Please do not hesitate to ask any questions (I have provided my contact details at the end of this sheet). I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

2. What is the purpose of this study?

There have been a number of significant outbreaks of *Clostridium difficile* within the UK over the past few years and research shows that the acquisition of *Clostridium difficile* while in hospital is a major patient concern. The proposed research is about Healthcare Associated Infection, in particular *Clostridium difficile*. It will look at how *Clostridium difficile* has been represented in local and national newspapers; explore risk perceptions of the public, healthcare and media professionals towards *Clostridium difficile* and look at how these risk perceptions vary. This study can help to identify gaps between scientific knowledge and public understanding and it will make recommendations as to how communication and the provision of information can be improved

There are three parts to the study;

- An examination of original newspaper articles about *Clostridium difficile*.
- Face-to-face focus groups with members of the public and healthcare professionals to explore risk perceptions and responses towards *Clostridium difficile*.
- Telephone interviews with media professionals (such as newspaper journalists and editors).

3. Why have I been chosen?

It is important for me to speak to healthcare professionals as well as members of the public to be able to identify any differences in perceptions about *Clostridium difficile* in order to identify any gaps between scientific knowledge and public understanding. This will also allow recommendations to be made about how healthcare professionals can better work with the public, the media and other stakeholders to ensure these relevant communication and correct information is provided.

4. Do I have to take part?

If you are interested in taking part, I would ask you to complete the short questionnaire attached which you can return to me by post in the stamped addressed envelope provided. The information requested (professional background, training age, gender etc.) will allow me to ensure that I recruit a range of healthcare professionals to the study. If you are agreeable to taking part in a focus group, you are asked to provide me with contact details (on the questionnaire). I will then get in touch to let you know if you have been selected for a focus group discussion and provide you with dates, times and venue if required. Whether you decide to take part or not is entirely your choice. You are under no obligation. If you do decide to take part, you may withdraw at any time and without giving any reason. This decision will not affect you in any way.

5. What will happen to me if I take part?

If you agree to take part, you will be invited to participate in a discussion with approximately 6-8 other healthcare professionals. I, as the researcher will act as the group 'moderator' by asking questions and facilitating further discussions. The aim of the focus groups is for me to learn more about your thoughts around *Clostridium difficile*. You will be notified of the venue for the focus group nearer the time, but you will not have to travel far. You will also be provided with light refreshments. Focus groups will be audio taped, provided that participants are agreeable, to help me to analyse the discussions.

6. What happens when the research stops?

Once the research study has been completed, a report of the findings will be written up for my PhD thesis. I also plan to hold dissemination sessions, to give you the opportunity to hear about the findings of this study. If you wish, you may contact me at any time to discuss the findings. Findings may also be presented at conferences and be published in peer-reviewed journals. In all cases, the anonymity of all participants is guaranteed at all times.

7. What Are The Benefits of The Study?

Clostridium difficile is a very serious concern. By exploring public, healthcare and media professional's perceptions of *Clostridium difficile*, it will enable me to identify ways to provide acceptable and appropriate public health information and look at ways in which we can ensure that the public are well informed about the risks they face. This will ultimately help to increase public confidence, enhance the patient experience, improve communication and reduce anxiety.

8. Will I have to give any personal details?

No personal information other than age, gender and professional background will be collected.

9. Will my taking part in the study be kept confidential?

Should you consent to taking part in the research, you will be allocated with a study number which will be used for all of the data collection. Any computer saved data relating to this project will only be accessible to me and my two supervisors at the university. It will also be kept on a password protected university computer in locked offices. All information obtained in the study, including audio tapes from the focus groups will be stored securely and destroyed once the study is completed. Neither you as an individual nor any healthcare organisation will be identifiable in any report.

10. Who is organising the research?

I am undertaking this study for my PhD within the University of Dundee, School of Nursing and Midwifery.

11. Who has reviewed the study?

The University of Dundee Research Ethics Committee has examined the proposal and has raised no objections from the point of view of ethics. It is a requirement that all research records are made available to monitors from the university whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

12. Contact for further information.

If you have any questions about this study please don't hesitate to contact:

Emma Burnett
Lecturer & Researcher, Infection Prevention and Control
University of Dundee, School of Nursing and Midwifery
11 Airlie Place,
Dundee, DD1 4HU
Tel: 01382 386876 mobile: 07866140891
e.burnett@dundee.ac.uk

Thank you for reading this information and considering participation in this study.

Appendix seven: Media professional participant information sheet

Participant Information Sheet Media Professionals

Understanding risk perceptions and responses of the public and media professionals: The case of *Clostridium difficile*

1. Invitation

I invite you to participate in a research project I am undertaking for my PhD at the University of Dundee, School of Nursing and Midwifery. However, before you decide whether or not you wish to participate, I'd like to explain a bit about the study therefore I am providing you with the following information. Please do not hesitate to ask any questions (I have provided my contact details at the end of this sheet). I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

2. What is the purpose of this study?

As you will be aware, there have been a number of significant outbreaks of *Clostridium difficile* within the UK over the past few years. The proposed research is about Healthcare Associated Infection, in particular *Clostridium difficile*. The study will address how *Clostridium difficile* has been represented in local and national newspapers and television; how this is influenced by outbreaks. It will also explore risk perceptions of the public and media professionals towards *Clostridium difficile* and look at how these risk perceptions vary. There has in some quarters, been criticism of media professionals for exaggerating and distorting of the newspaper stories. However, it has also been pointed out that very little attention has actually been paid to the working processes of journalists, especially when covering health care issues and how these affect what is reported and how it is reported. As you know, there are a number of constraints journalists face such as legal issues, regulatory codes of practice, training, external demands, competition among journalists and problems sourcing reliable information. This study can help identify gaps between scientific knowledge and public understanding and will make recommendations as to how communication and the provision of information can be improved

There are three parts to the study;

- An examination of original newspaper articles about *Clostridium difficile*.
- Face-to-face focus groups with members of the public to explore risk perceptions and responses towards *C. difficile*.
- Telephone interviews with media professionals such as newspaper journalists and editors.

3. Why have I been chosen?

It is important that I talk to journalists and editors in addition to members of the public to explore the complex processes through which stories are formed, written and published in order to understand the gaps between scientific knowledge, media reporting and public understanding.

4. Do I have to take part?

If you are interested in taking part, you should complete the short questionnaire included with this leaflet and send back to me in the stamped addressed envelope provided. I will then contact you to notify you if you have been selected to take part in the study and we can arrange a date and time for the interview. Whether you decide to take part or not is entirely your choice. You are under no obligation. If you do decide to take part, you may withdraw at any time and without reason. This decision will not affect you in any way.

5. What will happen to me if I take part?

If you agree to take part, you will be invited participate in a telephone interview with myself on a date and time that suits you. The aim of the interview is for me to learn more about how the media handle their stories and explore the challenges you face when reporting on such issues. The interview will be audio taped to help me analyse the discussions.

6. What happens when the research stops?

Once the research study has been completed, a report of the findings will be written up for my PhD thesis. If you wish, you may contact me to discuss the findings. Findings may also be presented at conferences and be published in peer-reviewed journals. In all cases, the anonymity of all participants is guaranteed at all times.

7. What Are The Benefits of The Study?

Clostridium difficile is a very serious concern. By talking to the public and media professionals, it will enable me to explore ways to provide acceptable and appropriate public health information and look at ways in which we can ensure that the public are well informed about the risks they face. This will ultimately help to increase public confidence, enhance the patient experience, improve communication and reduce anxiety.

8. Will I have to give any personal details?

No personal information other than age, gender and background will be collected.

9. Will my taking part in the study be kept confidential?

Should you consent to taking part in the research, you will be allocated with a study number which will be used for all of the data collection. Any computer saved data pertaining to this project will only be accessible to myself and my two supervisors at the university. It will also be kept on a password protected university computer in locked offices. All information obtained in the study, including audio tapes from the interview will be stored securely and destroyed once the study is completed. You will not be identified by name in any report.

10. Who is organising the research?

I am undertaking this study for my PhD within the University of Dundee, School of Nursing and Midwifery.

11. Who has reviewed the study?

The University of Dundee Research Ethics Committee has examined the proposal and has raised no objections from the point of view of ethics. It is a requirement that all research records are made available to monitors from the university whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

12. Contact for further information.

If you have any questions about this study please don't hesitate to contact:

Emma Burnett
Lecturer & Researcher, Infection Prevention and Control
University of Dundee
School of Nursing and Midwifery
11 Airlie Place
Dundee, DD1 4HU
Tel: 01382 386876
e.burnett@dundee.ac.uk

Thank you for reading this information and considering participation in this study.

Appendix eight: Healthcare professional questionnaire

If you are interested in participating in this study, please take a few moments to complete this questionnaire and return to me using the stamped addressed envelope provided. This will provide me with a range of information to help me select participants for my focus groups. **All information will be kept completely confidential.**

15. Occupation and grad/band

16. How long have you worked as a healthcare professional

17. Have you had any professional experience of *Clostridium difficile* (C.diff)? (briefly explain)

18. What is your highest level of education? (i.e. School, further education, diploma, degree, MSc, PhD)

19. Age (please circle)

16-25 years	26-35 years	36-45 years	46-55 years	56-65 years
-------------	-------------	-------------	-------------	-------------

20. Gender (please circle)

Male Female

21. Marital status: (please circle)

Married Divorced/Separated Widowed

22. Race/Ethnicity (please circle)

White (British/Irish)

Black & Black British (Caribbean/African/Other)

Mixed (White & Black Caribbean/White & Black African/White & Asian/Other)

Asian or Asian British (Indian/Pakistani/Bangladeshi/Other)

23. Religion or Belief

Christian Buddhist Hindu Jewish Muslim Sikh None

24. Have you had any personal experience of *Clostridium difficile* (C.diff)?
(briefly explain)

25. Do you regularly attend the hospital as a patient? (please circle)

Yes No

26. Have you had any hospital admissions in the last 12 months? If so, how many? (please circle)

Yes No If Yes, how many:

27. What newspapers do you read? (Local, regional and national)

Please indicate what days and times you would usually be available to participate in a focus group by ticking the relevant boxes.

Suggested Days	Suggested Times (Please circle)
Monday	Morning Afternoon Evening
Tuesday	Morning Afternoon Evening
Wednesday	Morning Afternoon Evening
Thursday	Morning Afternoon Evening
Friday	Morning Afternoon Evening
Saturday	Morning Afternoon Evening
Sunday	Morning Afternoon Evening

Please provide your contact details if you are willing to take part in a focus group discussion

Name:

Address:

Contact Telephone Number:

Email address:

How would you prefer me to contact you: Telephone or Email:

Thank you for taking the time to complete this questionnaire. Please return to me in the stamped address envelope provided and I will contact you soon to let you know if you have been selected to participate in this study. Please do not hesitate to contact me at any time if you have any questions. My contact details are on the participant information leaflet.

Emma Burnett

Appendix nine: Public focus group topic guide

Welcome and Introduction

Thank you very much for attending. Help yourself to tea/coffee/ juice and snacks.

Distribute name cards.

Obtain written consent and check approval for recording session.

Preamble:

Explain modes of discussion. Not an interview or a 'quiz'. Explain purpose of study. Do not need to know lots to take part. No right or wrong answers. I am just interested in what you have to say. What I really want is for us to have a conversation and to explore the issues, look at what you think individually and as a group. Don't worry about disagreeing with people. Try to hear from everyone in the group – talk to each other – not just to me.

Go round the room and ask everyone to introduce themselves. Start with me and the focus group assistant.

1. Have you come across information about *Clostridium difficile*?

Prompts: risks, causes, prevention, treatment, personal experience

2. What have been your main sources of information about *Clostridium difficile*?

Prompts: direct experience, family, friends, media, healthcare professionals, is it trustworthy

3. Have you talked about *Clostridium difficile* with anyone else?

Friends; family; colleagues; strangers

4. What concerns do you have about *Clostridium difficile*?

Prompts: going into hospital, yourself, family or close friend(s), illness, death, who is to blame for the current situation

5. If you go into hospitals (as a patient or visitor), do you do anything or take extra precautions to protect yourself?

Prompts: hand hygiene, cleanliness

6. Show participants some newspaper headlines. What do you think about these?

Prompts: are they helpful, scaremongering, inaccurate, believable, sources they use in their stories (experts, 'victims', celebrities, politicians),

7. Do you think there is a need to improve communication and information given to the public? If so, what type of things do you think could be done?

Prompts: Types of communication and information, healthcare organisations, via media, via any other sources

8. Would anyone like to add anything else before we finish?

Closure

Summarise discussions and recap the purpose.

Explain what my next steps are.

Thank everyone for coming and participating in the study.

Make sure all consent forms are signed and provide participants with thank you token.

Write to all participants thanking them for participating.

Appendix ten: Healthcare professionals focus group topic guide

Welcome and Introduction

Thank you very much for attending. Help yourself to tea/coffee/ juice and snacks.

Distribute name cards.

Obtain written consent and check approval for recording session.

Preamble:

Explain modes of discussion. Not an interview or a 'quiz'. Explain purpose of study. Do not need to know lots to take part. No right or wrong answers. I am just interested in what you have to say. What I really want is for us to have a conversation and to explore the issues, look at what you think individually and as a group. Don't worry about disagreeing with people. Try to hear from everyone in the group – talk to each other – not just to me.

Go round the room and ask everyone to introduce themselves. Start with me and the focus group assistant.

1. What are your thoughts about *Clostridium difficile*?

Prompts: risks, causes, prevention, treatment, personal experience

2. What concerns do you have about *Clostridium difficile*?

Prompts: working with infected patients, going into hospital yourself, family, close friend(s), illness, death, who is to blame for the current situation

3. What do you think are the public's main sources of information about *Clostridium difficile* and are they effective/relevant/trustworthy?

Prompts: direct experience, family, friends, media, government, healthcare professionals

4. If you go into hospitals yourself (as staff, patient or visitor), do you do anything or take extra precautions to protect yourself?

Prompts: hand hygiene, cleanliness

5. Show participants some newspaper headlines. What do you think about these?

Prompts: are they helpful, scaremongering, inaccurate, believable, sources they use in their stories (experts, 'victims', celebrities, politicians)

6. Do you think there is a need to improve communication and information given to the public? If so, what type of things do you think could be done?

Prompts: Types of communication and information, healthcare organisations, government, media, any other sources

7. Would anyone like to add anything else before we finish?

Closure

Summarise discussions and recap on the purpose.

Explain what my next steps are.

Thank everyone for coming and participating in the study.

Make sure all consent forms are signed.

Write to all participants thanking them for participating.

Appendix eleven: Focus group consent form

Title of Project: Understanding risk perceptions and responses of the public, healthcare and media professionals: The case of *Clostridium difficile*

Please initial box

1. I confirm that I have read and understood the information leaflet dated 17th March 2010 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that the data collected during the study will be looked at by the researcher and supervisory team within the School of Nursing and Midwifery, University of Dundee. ☐
4. I agree to take part in the above study. ☐
5. I have been provided with £15 as a token gesture for taking part. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Appendix twelve: Contact summary sheet

Contact Type:

Site:

Date:

Participants:

What were the main issues or themes that stuck you about this contact group?

Which research questions and which variables did the contacts bear on most centrally?

Were there any new speculations, questions, or hunches about the contacts?

Appendix thirteen: Media professional interview guide

Welcome and Introduction

Thank you for agreeing to participate in the study. Check approval for recording session.

Preamble:

Explain purpose of study. No right or wrong answers. I am just interested in what you have to say. What I really want is for us to have a conversation and to explore some issues.

1. **Tell me about yours and your editor's objectives when reporting on a story about risks such as *C.difficile*.**

Prompts: what makes a good story, public reassurance, educate public, alarm/shock, provoke reactions from public/healthcare professionals/government, news value, human interest factor, 'it could be you factor', reporting statistics, who decides on what to report and what not to report, how long a story should run for, front page,

2. **What challenges and barriers to you face when reporting on such stories?**

Prompts: competition from other newspapers (important to be the first to report), deadlines, conflicts with editors, using sources (experts/victims/politicians), own knowledge, importance of visuals, always believe what you write? Confident about reporting healthcare risk/C.diff stories?

3. **How much do you think that the way a particular story is reported affects and shapes the public's views about it?**

Prompts: very influential, not at all influential, do they believe what they read or not.

4. **How do you think healthcare professionals feel about how healthcare risks such as *C.difficile* are reported in newspapers?**

Prompts: do healthcare professionals understand the workings of the media, how good are they at getting their messages across in the media, critical

5. **You wrote this story on ----- about the *Clostridium difficile* outbreak at the Vale of Leven Hospital. Can you tell me more about how you went about this and what you were aiming to achieve?**

Prompts: explore areas within the story. use of specific words, use of sources, images, blame,

6. **Do you think there is a need to improve communication and information between yourselves and healthcare professionals? If so, what type of things do you think could be done?**

Prompts: Types of communication and information, healthcare organisations, via media, via any other sources

7. Would you like to add anything else before we finish?

Closure

Summarise discussions and recap the purpose.

Explain what my next steps are.

Thank you for participating in the study.

Make sure all consent forms are signed.

Write to all participants thanking them for participating.

Appendix fourteen: Data analysis plan

The purpose of a qualitative data analysis plan is to ensure that the researcher has a clear understanding of the principles that they intend to follow in gathering and making sense of the data. Additionally, a robust plan will project ahead to the kinds of analytics steps that will be taken to produce findings and answer the research questions (Thorne 2008). Without such a plan, the researcher risks failing to collect the data they need, becoming overwhelmed by the sheer volume of data and resulting in disparities between the research questions and findings and interpretations.

If there are a number of large data sets, the researcher must delineate the boundaries of their analysis with a comprehensive analysis plan (Namey et al 2007). An important part of that plan is to specify if all data sets are to be analysed together or separately. For each separate analysis the following key questions need to be answered:

1. What are the research questions?

1. How do public construct risk perceptions and respond to risk in the context of *Clostridium difficile*?
2. How do healthcare professionals construct risk perceptions and respond to risk in the context of *Clostridium difficile*?
3. Are there differences between public and healthcare professionals' risk perceptions and responses?
4. How and why do media professionals affect risk perceptions and responses?

2. What is the analytical purpose?

To gain an in-depth understanding of public, healthcare professionals and media professionals risk perceptions and responses within the context of *C. difficile*

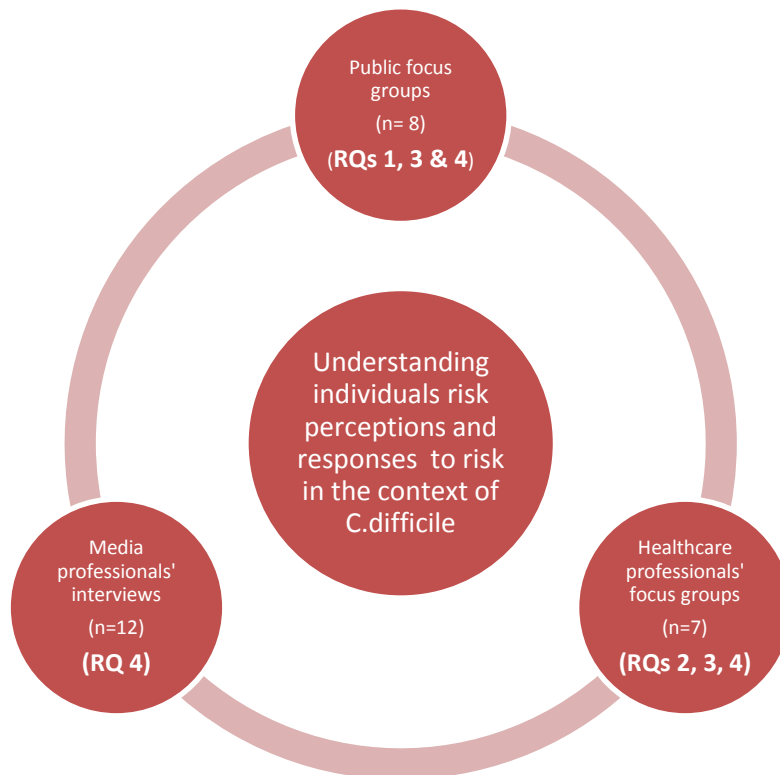
Begin with the theoretical framework which comprise of descriptive claims (forms the basis for the preliminary analytic framework) ~ then move towards interpretations (intellectual inquiry) that will illuminate the phenomenon under investigation in a new and meaningful manner (gradually takes distance from the theoretical framework as alternative conceptual emphases and intrigues arises)

3. What is the practical purpose of the analysis?

- To fill gaps in the literature (contribute to knowledge)
- To build on current theory
- To help inform clinical practice
- To help inform the application of future research to other healthcare risk issues

4. How is the analysis of the data sets connected to the research questions?

The analysis of the data sets will answer all four research questions as illustrated below:



Do I need to include media coverage? Is this muddying the water too much?

- The full media coverage analysis that I have already conducted (how has *C.difficile* been represented in print media) currently does not fit well with this plan.
- However, it could be used for supplementary data....perhaps to complement what the public, healthcare professionals or media professionals say?
- Alternatively, this could be left out of PhD and written up for publication.

What is to be asked of the data?

I need to be careful with this. As above I will begin with the theory (I need to start somewhere) – but must be very careful that I do not try to force my data into the theory and only conduct deductive analysis, thus staying purely descriptive. The inductive part of the analysis is extremely important (Miles & Huberman's framework is very good for guiding me through this process). To begin very early analysis I will develop broad propositions from the HBM to guide me.

How is the analysis going to be conducted?

Miles and Huberman framework

NVivo for storing and managing data

Two options:

1. *Analyse each data set separately and bring them altogether in a discussion chapter*
Pro: possibly easier to conduct (less messy)

Cons: risks not being able to tell a coherent, flowing story: being too disjointed; providing too many findings (possibly unrelated to the RQs): unable to provide clear/adequate explanations/interpretations

2. *Analyse them altogether*

Pros: can help keep my story tight and coherent; have a 'completeness' to my thesis; will keep me focused on the research questions; will be less challenging to progress through the explanation/interpretation process

Cons: trickier to conduct due to large data sets; data sets are not equal therefore I am not looking for the same thing in each (i.e. public & HCPs different to what I am looking for with the media professionals)

I feel much more drawn to the second option....

What resources will be needed to conduct the analysis?

Lots of time and patience!

NVivo

How is the data going to be presented?

One findings chapter and one discussion chapter if choosing option 2 above

What is the timeline for analysis?

I don't want to be too strict with this as I know analysis will take some time, but I would be keen to give myself a rough idea.... is around the beginning of next year too optimistic as a goal?

Lyn Richards (2005) and Bazeley (2009) lists five key signs which indicate that the analysis is sufficient:

- Simplicity: a small 'polished gem of a theory', rather than a mere pebble of truism
- Elegance and balance: it is coherent
- Completeness: it explains all
- Robustness: it doesn't fall over with new data
- It makes sense to relevant audiences

Broad thoughts about what kind of questions needs to be asked of my data?

Research questions	Questions
RQs 2 & 3 <i>Public and healthcare professionals</i>	How do they construct their risk perceptions? How do they make sense of risk? How do they tell their stories? Why do they tell the stories that they do? How do they respond to the risk issues they discuss (physically and emotionally)? How do they position themselves and how do they defend their perceptions/responses? How do they interact with each other?

<p><i>Media professionals</i></p>	<p>How do they make sense of each other's perceptions/responses? Do perceptions/responses change in any way through interaction? Do their responses align with their perceptions? Are there differences in perceptions and responses between and within groups? Are they saying different things but talking about the same thing? If so, how/why?</p> <p><i>In all of the above issues media discussions are embedded, but for further clarity, I have outlined the media-related questions below. The 'how' is related to the public and healthcare professionals and the 'why' is related to media professionals (why they affect RPs and responses – it is because of the way risk issues are reported. It is therefore important to understand what factors influence the way risk issues are reported.</i></p> <p>How do they make sense of media representation? How are media stories positioned within their risk perceptions? How do the media affect the way they respond to risk stories?</p> <p>What influences media professionals to construct risk stories in the way that they do? What are their challenges and barriers when constructing risk stories? How do they wish their readers to view their risk stories? How do they communicate with healthcare professionals when constructing risk stories? Can communication channels between themselves and healthcare professionals be improved/ strengthened?</p>
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Appendix fifteen: First level coding framework for focus groups

Codes	Description
Perceived severity	Discussions around the perceived of the impact of the infection
Perceived susceptibility	Discussions around who is perceived to be more susceptible to the infection and why
Experiences	Discussions about either direct or indirect experiences
Barriers of preventative measures	Discussions around situations whereby preventative measures cannot be implemented
Benefits of preventative measures	Discussions around the impact of the implementation of preventative measures/infection prevention and control practices
Uncertainty	Incidents of lack of knowledge or understanding about something
Trust	Discussions around who or what people feel they can trust to keep them safe/protect them from infection/harm
Distrust	Discussions around who or what people feel they cannot trust to keep them safe/protect them from infection/harm
Information provision	Discussions around how people gain their information and how they communicate
Responses	Discussions around how and why people respond to certain situation

Final first level coding deductive combined with inductive (on reading and re reading transcripts and listening to audio recording (data entered into NVivo). The first level codes were revisited and revised a number of times throughout this process

	Codes	Description
1	Perceived severity	Discussions related to the perceived of the impact of the infection
2	Perceived susceptibility	Discussions around who is perceived to be more susceptible to the infection and why
2.1	· themselves	
2.2	· others	
3	Vulnerability	Discussions of whom or what people perceived to be most vulnerable when talking about specific situations. This is different from susceptibility as people may be vulnerable in the wider sense depending on the situation (not just at risk of acquiring the infection)
3.1	· domestic staff	
3.2	· local hospital/services	
	· themselves	
	· nurses	
	· staff	
	· public	
	· others	
4	Experiences or events	Discussions about either direct or indirect experiences or events
4.1	· direct	
4.2	· indirect	

4.3	• old days	
4.4	• previous observations	
4.5	• non healthcare	
5	Barriers of action	Discussions around when action is prevented or made difficult
6	Benefits of action	Discussions around the positive impact of the action
7	Uncertainty	Incidents of lack of knowledge or understanding about something
7.1	• knowledge	
7.2	• fear of the unknown	
8	Trust	Discussions around who or what people feel they can trust
8.1	• doctors	
8.2	• nurses	
8.3	• managers	
8.4	• government	
8.5	• media	
8.6	• healthcare staff	
8.7	• friends and/or family	
8.8	• themselves	
8.9	• educationalists	
8.10	• others	
8.11		
9	Wrong doing	Discussions around who or what people feel they are not doing what they should be doing
9.1	• doctors	
9.2	• nurses	
9.3	• managers	
9.4	• health board	
9.5	• government	
9.6	• media	
9.7	• public/patients	
9.8	• society/culture	
9.9	• healthcare staff	
9.10	• domestics	
9.11	• authority	
9.12	• educationalists	
9.13	• experts	
9.14		
10	Accountability	Discussions about lack of accountability of demonstration of being accountable
10.1	• staff	
10.2	• patients and/or public	
10.3	• government	
10.4	• health board	
10.5	• media	
11	Receiving information	Discussions around how people talk about gaining information
11.1	• strategies	
11.2	• challenges	
	• being visible	
12	Communicating information	Discussions around how and why people communicate to others about risk information
12.1	• strategies	
12.2	• challenges	
13	Responses	Discussions around how and why people respond to certain situation
13.1	• active	
13.1.1	○ to protect oneself	
13.1.2	○ to protect others	
13.2	• passive	

13.2.1	○ dismissing	
13.2.2	○ avoidance	
13.2.3	○ refusing to believe	
13.2.4	○ emotion	
13.2.5	○ feeling dirty	
13.2.6	○ acceptance	
13.2.7	○ frustration	
14	Perceived role	Discussions around their perceptions of their own role
14.1	· as a professional	
14.2	· in society	
15	What is needed	Perceptions of what is needed to improve specific situations

Appendix sixteen: First level coding framework from interviews

Codes	Description
Objectives	What journalists want to achieve when reporting about something
What to report	What makes a good story
What not to report	What makes a not-so-good story
Engagement with others	Speaking to contacts about particular issues
Strategies for locating sources	What journalists do to locate sources
Barriers when reporting	What challenges do journalists face when reporting
Relationship between journalists and newspapers	What type of working relationships do journalists have between themselves and other newspapers

Appendix seventeen: Final pattern coding framework from focus groups

No.	Pattern code	Description	Transcript excerpt	
			Public	Healthcare professionals
1	Perceptions of vulnerability	Discussions of whom or what people perceived to be vulnerable when talking about specific situations.		
1.1	In the firing line	Participants talk about criticisms about individuals that are made by others	<i>"Lorraine Kelly, she turned round and said 'the domestic's used the same mop all over the hospital' and when that happened, that's when all the domestics were getting spat on and everything in the street"</i>	<i>"I think they're [the nurses] scared about telling them [the visitors] the wrong information really. I think that's the problem – they fear that they are not gonna give them the right information and then that's when they come back and bite them"</i>
1.2	Working at the hard end of the stick	Participants talking about how challenging it is for healthcare professionals	<i>"I actually had a conversation with an auxiliary when I was in the heart ward and she was saying 'how am I supposed to get this cleaned' and there were 6 or 7 doctors all standing at reception and she couldn't get anywhere near the rooms for them"</i>	<i>"Working hard every day and doing the best that you can do, sometimes having no staff, not having a great deal of support and patients constantly coming through the system. I'm not surprised that a lot of nurses are burnt out"</i>
1.3	Fear	Participants talking about what is frightening to themselves and others	<i>"I was totally and utterly stressed out the whole time I was there. I wasnae ready to be sent home. I had just had a heart attack and wasnae ready to be sent home...just being in there, it was horrendous!"</i>	<i>"It's always bad you hear in the media" and I think that creates fear in patients who come into hospital, you know, they've got this great fear"</i>

1.4	Locality	Participants talking about the vulnerability of their local area	<i>"I think to be honest with Hospital X, if it hadn't been this whole C.diff think, it would have been something else to run with because they are just closing it down ward by ward"</i>	<i>"They don't really happen from here [C.difficile] we do get them from Hospital X. Patients come from hospital X and bring it to here"</i>
2	Rationalising competence	Discussions about theirs and other people's competence. To make judgements about risks people need to make judgements about people who manage the risks		
2.1	Doing the right thing	Discussions about themselves or others being competent and 'doing the right thing'. Participants mainly talked about their own competence.	<i>"It is the public I think [...] it's hand washing [...] I've got three grandchildren and I tell you I am hot stuff on that with them, but the number of times you go to public toilets and you see ladies coming out and they either don't wash their hands or they just run them under the water and away they go"</i>	<i>"In my career, I've usually been brought in when it's been a complete disaster and it's me scraping the relatives off the ceiling and explaining to them the what and why and how and then they go "if only I had understood that"</i>
2.2	Being knowledgeable	Participants' discussion about their perceptions of themselves and others in having good knowledge.	<i>""</i>	<i>"That's it, we're educated about it, the general public aren't"</i>
2.3	Being reassured	Discussions about specific people or situations that reassure participants of competence.	<i>"They had only so many cases and they were all right and now they got still maybe two or three, but it seems to have stopped and didn't get going mad or killing anybody"</i>	<i>"The gels from Boots or from Tesco or Asda. Women carry them in their bags now which didn't happen before"</i>

3	Attribution of responsibility	Talking about who and why they feel people are responsible for what they perceive to be the situation.		
3.1	Questioning competence	Participants questioning competence of specific people/organisations	<i>"My sister was in for an operation on her bowel and her bladder in X and she was lying basically in blood and she asked to get cleaned and it took them hours"</i>	<i>"Why do you need to learn academic to be a nurse? You don't. Doctors are there, doctors diagnose, doctors prescribe. That's not why nurse became nurses. They've lost that contact and I think that's why families don't respect you anymore"</i>
3.2	"Not like the old days"	Participants talking about the 'good old days' and their comparisons to now.	<i>"Nurses didn't get out in the street with their uniform. Now trainers as you know... It was smooth ward shoes that we had to wear"</i> <i>"Yeah they were nice girls then"</i>	<i>"I find that really hard because I'm an old nurse and really protective. I think they've [nurses] got far less time to care... I am not certain that these girls actually want to be nurses"</i>
3.3	Lack of knowledge	Participants perceptions of people's lack of knowledge	<i>"I don't think anyone actually has a clue cos nobody has actually put it down on paper – what the symptoms are what you can actually do about it, what it does to your body"</i>	<i>"I don't think they [the public] fully understand what C.diff is and I don't think they understand how you get it. They automatically think that cos somebody's got C.diff, it's because of the hospital, but it isn't necessarily the case"</i>
3.4	Lack of authority			

		Participants discussing their perceptions of the lack of authority which causes other people to behave in an incompetent way.	<i>"I think that's very much left up to the visitor. They've got those things [alcohol hand rubs] and there's nobody saying "excuse me, before you go into that ward, did you wash your hands?"</i>	
4	Evaluations of the communicators	Discussions about participants perceptions of the main communicators (experts and the media)		
4.1	The media: <i>'the bad, the bleak and the miserable'</i>	Participants making sense of media representation	<i>"I always think that the newspaper are now telling you all the negative things about it but they're no really telling you what it (C.difficile) actually is"</i>	<i>"the press are really good at whipping up peoples interest by using all these words that are eye catching but not necessarily accurate"</i>
4.2	The experts: <i>'who really knows what's going on?'</i>	Participants making sense of how the 'experts' communicate information	<i>"I felt it was really lax and if you went and complained you were looked at as a trouble maker"</i>	<i>"Every year an expert tells you what you're going to die of, then it doesnae happen. We had SARS, Bird Fly. Ever year an expert tell you and they stock up on all sorts of vaccines and you think, are people getting the best possible advice?"</i>

Appendix eighteen: Final pattern coding framework from interviews

No.	Pattern code	Description	Transcript excerpt
1	Role perceptions	How journalists see their role when reporting health risk related stories	
1.1	To report or not to report	What makes a story worthy of reporting	<i>"F*** me Doris!'</i> If you've got a story that's a 'f*** me Doris', it's the idea that the bloke's sitting reading the paper and he says 'f*** me Doris look at this!'"
1.2	Making the complex simple and memorable	Taking complex information given to them via sources and reporting it in a manner that the public will understand and remember	<i>"a lot of the information we give has to be boiled down from big reports and complicated tables that are published [...] So newspapers have to kind of... you know, we have to sort of translate it in a way."</i>
1.3	Analyse, probe and uncover	To be an advocate for the reader and find out what is going on.	<i>"If you're defensive, they're coming at you, making assumptions that you're hiding stuff".</i>
1.4	Influencing the political agenda	How journalists force politicians to take action	<i>"I certainly think if they hadn't got in touch with us and we ran that story, and again a whole bunch of them, more of them got in touch with us and it kind of gathered momentum. I think if it didn't go like that, you know, I don't think it would have got to the stage of a public inquiry".</i>
1.5	Fitting with the newspaper	What journalists do when writing for particular newspapers	<i>"I think it probably does to an extent in the broadsheet press, but probably less so in the tabloid press".</i>

2	Challenges of health risk reporting	What challenges and barriers journalists face when reporting health risk related stories and how they overcome them	
2.1	Whose agenda	Weary of being used to drive forward other people's agendas	<i>"Health is about political football. Absolutely it is, and I mean, we are going to see that again, um, very strongly in the run up to the next election in Scotland. Um, the politics of it is fascinating. The politics of it is really fascinating. And of course, then you get... and it's internal politics as well as external politics. Everybody just playing stuff off against one another"</i>
2.1	Getting the right information from the right people at the right time	Challenges of speaking to the most appropriate sources in order to get the best information prior to deadlines	<i>"Suddenly its three o'clock in the afternoon with a first edition deadline, sort of, three or four hours away, you know? If it's an outbreak and this story is live and its happening, you're trying to deal with the simple facts of it at that stage, and maybe, you know, we are not scientists, you are having to sort of scurry around, trying to dig up experts whether that opposition health spokes people or medics that we know, or personal contacts."</i>
2.3	Journalistic autonomy	How much or little autonomy journalists have over their stories	<i>"My editor changed a couple of details that I think it got a bit confused in the process, so when it went into the paper there were errors in it that I hadn't written and there were a couple of complaints and that's quite a frustrating thing".</i>
2.4	Competing with others	Level of competition between journalists and newspapers	<i>"Here was a bit more pressure on everyone from the editors then, because it's a frenzy, it's an absolute feeding frenzy and everyone wants something".</i>
2.5	Learning on the job	Training received by journalists in order to report on specialist health issues	<i>"If it's an outbreak and this story is live and its happening, you're trying to deal with the simple facts of it at that stage, and maybe, you know, we are not scientists".</i>

Appendix nineteen: Newspaper sample pool

National Broadsheets

Newspaper	Political Spectrum	High/Low Brow	Readership
*The Telegraph	Daily Right Wing	High Brow	1,843,000
The Financial Times	Centre Right	High Brow	430,000
*The Guardian	Left Wing	High Brow	1,205,000
The Independent	Liberal leaning	High Brow	679,000
*The Times	Centre Right	High Brow	1,801,000

National Tabloids

Newspaper	Political Spectrum	High/Low Brow	Readership
*The Daily Mail	Right Wing	Middle Brow	4,846,000
The Record (?Scottish)	Left Wing	Low Brow	1,092,000
*The Mirror	Daily Left Wing	Low Brow	3,566,000
The Daily Star	Right Wing	Middle Brow	1,471,000
The Express	Right Wing	Middle Brow	1,624,000
*The Sun	Left Wing	Low Brow	7,860,000

Sunday National Papers

Newspaper	Political Spectrum	High/Low Brow	Readership
The Telegraph	Right Wing	High Brow	1,672,000
The Observer	Liberal leaning	High Brow	1,374,000
Independent on Sunday	Left Leaning	High Brow	646,000
*Sunday Times	Centre Right	High Brow	3,194,000

Sunday Tabloid Papers

Newspaper	Political Spectrum	High/Low Brow	Readership
Mail on Sunday	Right Wing	Middle Brow	5,466,000
The Sunday Mail	Right Wing	Middle Brow	1,243,000
Sunday Express	Right Wing	Middle Brow	1,676,000
Sunday Mirror	Left Wing	Middle Brow	3,893,000
*News of the World	Left Wing	Low Brow	7,850,000

Regional Paper: The Herald

* Purposively selected for media analysis sample

Appendix twenty: Media coverage coding template

Clostridium difficile in the Newspapers

Coding Template

This first coding template provides details of the initial thumbnail categories, intermediate categories and conceptual categories and the initial codes. For the purpose of this analysis *a priori* codes and inductive codes have been generated. Alongside further reading and re reading of the newspaper articles, this template will help to identify and refine codes and collating them into potential themes. (Researchers thoughts in red)

Thumb nails/Template Categories

Newspaper	Daily Mail
Date	12 th June 2008
Headline	Revealed, how 22 patients died in six months in just one hospital after contracting C.diff
Journalists name/gender	Stuart Nicolson/male
Journalist speciality (if known)	Scottish political editor
Journalists email address	Stuart.Nicolson@dailymail.co.uk s.nicolson@dailymail.co.uk
Type of article	News report
Length of story & page	761 words: Page 4
Sources used	LibDem spokesman Ross Finnie Professor John Coia: Director of C.diff reference lab Dr Sayed Ahmed: Head of Outbreak Team

Intermediate categories

Category 1: Headline	<i>This relates to how the headline of the story has been created and used to capture it's audience</i>
Revealed, how 22 patients died in six months in just one hospital after contracting C.diff	Sensationalism: Linguistic syntagms: attracts attention. Wants readers to perceive C.diff as a rapidly spreading killer (use of 'just one hospital'). Readers will want to read the rest of the story to find out which hospital. Readers will also decode this headline to make presumptions about the content. These numbers will stick in their minds now (even though they are rather misleading) See below.

Category 1: Story type	<i>This relates to how the journalist has structured the story which indicates how he/she wants to draw the audience in.</i>
Sensationalism Debate Horror stories Outrage Letters Personal accounts/transformational stories	<p>Sensationalism/panic: focuses on the number of deaths. Mentions the 027 strain being '20 times more toxic that the normal form of illness'. Indicates that they want readers to think that it is this strain that caused the deaths</p> <p>Structured around the increase in incidences and how 'deadly' C.diff is.</p> <p>'number of cases may just be the tip of the iceberg..' These are journalists own words, written early on in the story, but says experts believe this. The 2 dots at the end of iceberg leaves reader to imagine the worse.</p> <p>Refers to MRSA (which most of the public will be familiar with and frightened of). Says C.diff is around 3 times more deadly. Wants to panic readers?</p> <p>Also looks for reasons and sews the seeds about who is to blame (health chiefs). Public like to identify with a 'bad guy'</p>

	Provides factual information about C.diff at end. Uses the terms 'can be fatal', 'it is extremely contagious'. Use of journalists own words.
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Category 2: Statistics	<i>This relates to how the journalist uses statistics relating to death, incidence and previous figures</i>
Deaths Incidences Previous figures Comparisons with other areas/countries	<p>Misleading use of stats: headline and first paragraphs state that 22 patients died, yet goes on to say that it was the cause of death in 8 patients, and a contributory factor in another 8. The remaining 8 had C.diff but died of unrelated causes.</p> <p>States 54 patients have been treated for C.diff, but all are not related to the hospital. State than numbers are high than normal</p> <p>Use of high numbers to mislead readers. They could already form perceptions before reading further. They will remember these high figures and relate to them.</p> <p>Compares incidence to Canada, Finland and Netherlands which has already 'claimed hundreds of lives'.</p> <p>Speaks about elsewhere in the UK and North America where they have shown significant reductions due to using fewer antibiotics. Public could think that this is the cause of the outbreak?</p>

Category 3: Sources	<i>This relates to the type of people the journalist uses in the article as sources and in what way does he/she use them</i>
Type of source Political Experts Victim Family member	LibDem health spokesman Ross Finnie: portrayed as a 'good guy': "serious failings by health chiefs" 'we need to know the truth about the cause of the increase in the levels

<p>Use of quotes</p> <p>How sources are portrayed in the article</p> <p>Good guy</p> <p>Bad guy</p>	<p>of C.diff. <i>Is on the public's side. Implies something is being held back/covered up?</i></p> <p>Says '...but rather a complete failure of the health board to stay on top of virus control'. <i>Public persuaded to think health board is to blame/covering up. Also, C.diff is a bacterium not a virus. Public will think this</i></p> <p>Professor John Coia: speaks about curbing antibiotic use as this can increase incidence of C.diff (see above)</p> <p>Dr Syed Ahmed: indicates that the outbreak is not to do with the strain, but that they are elderly and vulnerable to infection: <i>put at the end of the story, indicates that journalist does not see this as 'important'. Possibly wants to make readers think he is trying to 'cover up'/protecting the hospital/protecting himself. ?Readers will not believe this after reading previous text.</i></p>
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Conceptual Categories

Category 1: <i>Clostridium difficile</i>	<i>This relates to how the story portrays Clostridium difficile and what impact it is trying to achieve. What is the purpose of using such a source?</i>
Terms used	<p>Calls it C.diff. Doesn't use terms such as 'superbug'</p> <p>Refers to it as 'deadly'</p>
Category 2: Affected patients	<i>This relates to how the journalists portrays the patients affected to draw the readers in</i>

<p>Emotive language Elderly Vulnerable Innocent victims Young</p>	<p>Highlights that patients were mostly elderly. Public can all relate to someone close to them being elderly, fragile and vulnerable. Causes outrage, anger Facts at end state that children can be affected. Shock – parents? Public who are in hospital at that time or going in - panic</p>
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Category 3: Causes	<i>This relates to what is being perceived as the cause of the outbreak</i>
<p>Elderly patients Antibiotics Hand Hygiene Doctors practice Nurses practice Cleanliness Lack of isolation facilities</p>	<p>Health bosses mentioned, but not quoted. They have ordered an urgent review of antibiotic use. Professor Coia also mentioned antibiotics. Mentioned twice - Public initially think this is the cause?</p> <p>There is also an implication about poor hand washing as the 'hand hygiene chief has been drafted in to make sure hand washing rules are strictly followed'</p>

Category 4: Blame	<i>This relates to what or who is being 'blamed' for the outbreak in the story</i>
<p>Organisation Management Politicians Cost cutting Ignoring important evidence Impervious to concerns</p>	<p>The blame in this story definitely lies with the health bosses for 'serious failings'</p> <p>Overuse of antibiotics. Not directly said Implication of poor hand washing. Not directly said</p>

Category 4: Solutions/Actions	<i>This relates to what solutions or actions are being taken as a result of the outbreak</i>
<p>Review policy Antibiotics</p>	Antibiotic policy review

Hand hygiene Isolation	Hand hygiene chief – ‘drafted into the hospital to make sure hand washing rules are strictly followed’. Hand hygiene co-ordinators were already in post during this period so they were actually already there. Also implies this could be the cause....
Outbreak Control Team	
Closure of wards/hospital	
Bringing in of ‘experts’	
Independent Inquiry	
Audit	

Overall Impression

First major story. Sensationalised headline, Very sensationalised story with the focus being on numbers of deaths and implications that the situation is far worse. Starts to introduce someone to ‘blame’ (health chiefs), which helps form and shape public perception. Uses powerful political people to imply this and portrays them as being on the ‘public’s side’

One of first stories which would have created initial outrage and panic (for those who have connections with the hospital)